Reconceiving the Spoiled Female Identity:  
Childbearing and Motherhood among Women with 
Hepatitis C

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THE AUSTRALIAN NATIONAL UNIVERSITY

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Declaration of Originality

I hereby declare that this submission is my work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person, no material which to a substantial extent has been accepted for the award of any other degree or diploma of a university or other institute of higher learning, except where due acknowledgement is made in the text.

Signed

______________________
H. Clare Thetford

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To my family, thank you for all your endless love and encouragement during all of the ups and downs. Despite being on the other side of the world you were only ever a phone call away and always assured me that everything would be okay.
Abstract

This thesis explores the impact of hepatitis C on women’s childbearing decisions and experiences of motherhood. A partial grounded theory approach was used, in which 34 women living with hepatitis C participated in semi-structured interviews to determine the direct and indirect effects of hepatitis C on their own personal decisions regarding childbearing and to describe their lived experiences of motherhood. The qualitative interview data were analysed thematically, in which common themes were identified and explored.

Three key areas are explored: women’s social experience of hepatitis C; hepatitis C and childbearing decisions; and the meaning of motherhood for women with hepatitis C.

The interviews revealed that living with hepatitis C had direct effects on the childbearing decisions of women. The direct effects of the virus which impacted on women’s childbearing decisions included poor physical and emotional hepatitis C related health, the perceived risk of vertical transmission of hepatitis C, concerns their future hepatitis C related health might impact upon their mothering abilities, and childbearing can conflict with treatment for hepatitis C. However, of greater importance to these women, appeared to be the indirect effects of living with a virus which is so highly stigmatised within our society. In particular, hepatitis C is closely associated with injecting drug use, which means these women are often assumed to possess the stereotypical characteristics associated with injecting drug users. As a result, they experience widespread medical discrimination and social rejection. Hepatitis C also impacts indirectly upon a wide range of factors that most women in contemporary society take into consideration in their childbearing decisions, for example, available social support, financial security and age.
The experiences reported by these women are discussed in terms of their concordance or discord with prevailing theories of deviance, stigma and the social construction of motherhood. The interview data, considered in light of such theories reveal that possibly the greatest impact that hepatitis C can have upon women is to prevent them from achieving a legitimate adult female status through childbearing and becoming a ‘good mother’.

The implications of these findings are discussed in terms of public health and social policy.
# Table of Contents

Declaration of Originality ........................................................................................................ ii

Acknowledgements ...................................................................................................................... iii

Abstract .......................................................................................................................................... iv

List of Tables and Figures .............................................................................................................. x

List of Appendices ......................................................................................................................... xi

Glossary ........................................................................................................................................... xii

**Section 1: Introduction and Literature ..................................................................................... 1**

Chapter 1: Childbearing and Motherhood among Women with Hepatitis C ......................... 2
  Hepatitis C ................................................................................................................................... 3
  Natural history of hepatitis C in children .................................................................................... 5
  Routes of infection ....................................................................................................................... 6
  The epidemiology of hepatitis C ................................................................................................. 7
  Living with hepatitis C .................................................................................................................. 12
  Treating hepatitis C ..................................................................................................................... 13
  Aims of the thesis ....................................................................................................................... 15
  Significance of the research aims ............................................................................................ 15
  Existing studies on the social aspects of hepatitis C ................................................................. 17
  The evolution of the research question ....................................................................................... 18

Chapter 2: Women with Hepatitis C ................................................................................................. 19
  Sex ratio of infections ................................................................................................................ 22
  Characteristics of women with chronic hepatitis C ................................................................ 23
  Gender specific issues of hepatitis C ....................................................................................... 28
  The risk of vertical transmission of hepatitis C ...................................................................... 28
  Risk of transmission via breastfeeding .................................................................................. 30
  Mode of delivery and risk of vertical transmission ................................................................. 31
  Sexual transmission of hepatitis C .......................................................................................... 31
  Hormonal and menstrual irregularities and birth control ....................................................... 32
  Natural history of hepatitis C in women ................................................................................ 33
  Quality of life of women living with chronic hepatitis C ......................................................... 34
  Summary: Women and hepatitis C ......................................................................................... 35

Chapter 3: Gender and Injecting Drug Use ...................................................................................... 37
  Drug treatment .......................................................................................................................... 42
  Summary: Gender and injecting drug use ............................................................................. 43

Chapter 4: Deviance, Stigma and Women Living with Hepatitis C ............................................ 45
  Deviance theory ....................................................................................................................... 47
  Primary and secondary deviance .......................................................................................... 51
  Hepatitis C and secondary deviance ....................................................................................... 52
  The falsely accused ................................................................................................................... 53
  Deviant labels become the master status ............................................................................. 54
  Hepatitis C and auxiliary traits ................................................................................................. 55
  Auxiliary traits of women with hepatitis C ........................................................................... 56
  Living a double life ................................................................................................................ 57
  Stigma ....................................................................................................................................... 58
  Illness as deviance .................................................................................................................. 61
Chapter 5: The Social Construction of Motherhood and Women with Hepatitis C

Section 2: Research Methods

Section 3: Findings
Summary: Women with hepatitis C have lower levels of social support and this affects their childbearing decisions ................................................................. 249
Injecting drug use affects childbearing decisions among women with hepatitis C .... 250
Existing children and hepatitis C related childbearing decisions ......................... 264
Summary: Hepatitis C and injecting drug use impact on childbearing decisions ...... 265

Chapter 10: The Meaning of Motherhood for Women with Hepatitis C ............... 267
The desire to be a mother ................................................................................. 267
Choosing to be childless .................................................................................. 269
How does having hepatitis C affect mothering? ............................................. 274
Supports ............................................................................................................. 274
Formal supports ................................................................................................. 274
Informal supports .............................................................................................. 276
Infection control ................................................................................................. 277
Managing the physical symptoms of hepatitis C and motherhood ................... 278
Employment ....................................................................................................... 283
Why are women with hepatitis C considered to be inadequate or bad mothers?... 284
The values involved in ‘good mothering’ ......................................................... 285
Having children removed from custody .......................................................... 288
Summary: The meaning of motherhood for women living with hepatitis C ......... 290

Section 4: Discussion and Conclusions ............................................................. 293

Chapter 11: Discussion and Conclusions ........................................................ 294
Stigmatisation .................................................................................................... 295
The sick role ....................................................................................................... 301
Medicalisation ................................................................................................. 303
Mothering and the female identity ................................................................... 304
Conclusions ...................................................................................................... 306
Policy recommendations and future research directions .................................. 310
Significance of the findings .............................................................................. 319
Limitations of the thesis and future research directions .................................... 320

References ........................................................................................................ 322
Appendices ........................................................................................................ 355
List of Tables and Figures

Figure 1: Barnardos Australia May 2003 Appeal ................................................................. 85
Table 1: Demographic characteristics of the sample .......................................................... 127
Table 2: Age distribution of sample .................................................................................. 131
Table 3: Income distribution of sample .............................................................................. 133
Table 4: Educational attainment ....................................................................................... 135
Table 5: Injecting drug use .................................................................................................. 136
Table 6: Source of hepatitis C infection ............................................................................. 139
Table 7: Estimated duration of hepatitis C infection .......................................................... 140
List of Appendices

Appendix 1: Suburb of residence........................................................................................................355
Appendix 2: Hepatitis C summary table..........................................................................................356
Appendix 3: Injecting drug use and methadone programme enrolment summary table...360
Appendix 4: Social supports ..............................................................................................................361
Appendix 5: Hepatitis C and childbearing.........................................................................................366
Appendix 6: Summary of childbearing decisions and dilemmas relating to hepatitis C.....370
Appendix 7: Participant profiles .......................................................................................................375
Appendix 8: Information and consent form.......................................................................................392
Appendix 9: Copy of questionnaire...................................................................................................395
Appendix 10: Interview schedule......................................................................................................397
Appendix 11: Data coding scheme....................................................................................................398
Appendix 12: Hierarchical coding scheme.......................................................................................401
**Glossary**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>IDU:</td>
<td>Injecting drug use</td>
</tr>
<tr>
<td>Injector:</td>
<td>Injecting drug user</td>
</tr>
<tr>
<td>HREC:</td>
<td>Human Research Ethics Committee</td>
</tr>
<tr>
<td>DoCS:</td>
<td>Department of Community Services</td>
</tr>
<tr>
<td>LFT:</td>
<td>Liver function test</td>
</tr>
<tr>
<td>PCR:</td>
<td>Polymerase chain reaction test</td>
</tr>
<tr>
<td>SES:</td>
<td>Socioeconomic status</td>
</tr>
<tr>
<td>WLHC:</td>
<td>Women living with hepatitis C study</td>
</tr>
<tr>
<td>MMT:</td>
<td>Methadone maintenance treatment</td>
</tr>
<tr>
<td>ANU:</td>
<td>Australian National University</td>
</tr>
<tr>
<td>NDARC:</td>
<td>National Drug and Alcohol Research Centre</td>
</tr>
<tr>
<td>NCHECR:</td>
<td>National Centre in HIV Epidemiology and Clinical Research</td>
</tr>
<tr>
<td>ANCAHRD:</td>
<td>Australian National Council on AIDS and Related Diseases</td>
</tr>
</tbody>
</table>
Section 1: Introduction and Literature

In this section, the research question is introduced and contextualised within existing literature. There are five chapters within this section:

Chapter 1: Childbearing and motherhood among women with hepatitis C
Chapter 2: Women with hepatitis C
Chapter 3: Gender and injecting drug use
Chapter 4: Deviance and stigma
Chapter 5: The social construction of motherhood
Chapter 1: Childbearing and Motherhood among Women with Hepatitis C

The doctor basically said I can’t have children. I am going to infect my children. I really thought I could never have children and I am going to die within 20 years. *Becky*

When you’re a mother, even when you’re sick, you need to carry on. And I was really, really sick, and I still had to carry on in the morning and take [baby] to day care. *Sarah*

I was thinking I haven’t even healed my body and I’m trying to get rid of this disease and stuff. Would I be able to cope financially? Would my body be able to cope when I get too fatigued? Emotionally, would I be able to have this child in my life? *Fiona*

Hepatitis C is a blood borne, potentially debilitating virus that carries considerable social stigma. This thesis explores the ways in which living with this virus can impact upon childbearing decisions and the experiences of motherhood. The quotes above are taken from interviews with women living with hepatitis C, and indicate just a few of the issues they face regarding childbearing and motherhood.

The thesis draws upon sociological theories of stigma and deviance, and the social construction of motherhood, in addition to literature from demography, public health and the drug and alcohol field. The social construction of risk is considered briefly through the examination of the perceptions of risks involved in the vertical transmission of hepatitis C. Many women living with hepatitis C experience social stigma and marginalisation (Gifford, O’Brien, Bammer, Banwell et al., 2003; Hopwood and Southgate, 2003). Much of this

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1 Vertical transmission refers to infant and childhood acquisitions of hepatitis C from the biological mother.
marginalisation is related to injecting drug use (IDU)^2, which is the primary mode of hepatitis C infection in Australia. Hepatitis C is an infectious disease and this creates further stigma and discrimination, as it carries with it notions of pollution and is also perceived to pose a threat of infection to others.

**Hepatitis C**

Hepatitis means inflammation or swelling of the liver and can be caused by chemicals, drugs or viruses. Hepatitis C is a form of viral hepatitis, transmitted through blood-to-blood contact. Hepatitis C was identified in 1989 (Choo, Kuo, Weiner, Overby et al., 1989) and accounts for 90 per cent of non-A non-B hepatitis viral infections. A diagnostic and screening test was developed soon after (Kuo, Choo, Alter, Gitnick et al., 1989). It became a notifiable disease^3 in Australia from 1990 (Dore, Law, MacDonald and Kaldor, 2003). The natural history of hepatitis C infection remains contentious, largely because the onset of disease is only rarely recognised and the course of progression occurs over a long time period (Seeff, 2002). Of every 100 people who acquire hepatitis C infection, approximately 25 per cent spontaneously clear the virus. Infections that last under six months are known as acute infections, but some of these can continue and go on to become chronic infections. Some people may experience symptoms during the acute stage, but most do not and may not be aware that they became infected at all. After six months, the remaining 75 per cent of people who have not cleared the virus go on to develop chronic (long term) hepatitis C infection. Many people with chronic hepatitis C are asymptomatic, or only experience mild and fluctuating symptoms. For some people, however, hepatitis C can be

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^2 Injecting drug use will be referred to as ‘IDU’ and injecting drug users will be referred to as ‘injectors’ throughout this thesis.

^3 As a notifiable condition, doctors and laboratories are required to send case reports to public health authorities.
pernicious. Hepatitis C can be a degenerative condition. Symptoms can become more severe and more frequent the longer the duration of infection. Symptoms include lethargy, nausea, pain, abdominal discomfort and jaundice. Over time, the liver can become damaged by the virus, which can cause these symptoms. The data presented here on the natural history of hepatitis C are estimates based upon limited knowledge of the virus. Of every 100 chronic infections, an estimated 26 per cent may never experience any illness associated with the virus. The remaining 65-80 per cent of people may develop signs of illness on average 15 years after infection but these can range in severity and duration. After 30 years 6-26 per cent of people develop liver cirrhosis (liver damage), which after a further several years can lead to liver failure or liver cancer in two to five per cent of people (Commonwealth of Australia and Australian Institute for Primary Care, 2001). Liver failure can be treated with a liver transplant but the new liver will also become infected with hepatitis C. Some factors have been identified with increased risk of liver fibrosis (liver damage), which include older age, higher levels of alcohol consumption, being male (Danta, Dore, Hennessy, Li et al., 2002; Poynard, Bedossa and Opolon, 1997) and co-infection with HIV or hepatitis B (Dore, Freeman, Law and Kaldor, 2002). Overall, the risk of progression to severe liver disease is highly variable (Dore et al., 2002) and outside of the few associations highlighted above, individual prognosis is very difficult to ascertain. In and of itself, hepatitis C only rarely leads to death. There is no vaccine available, although there are some treatments for hepatitis C. Medical and social understanding of the virus is still in its infancy and requires considerably more research.

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4 Hepatitis C was the primary cause of liver disease among 151 liver transplants in 2002 (NCHECR, 2003).
Natural history of hepatitis C in children

Comparatively little is known about the epidemiology, natural history and response to treatment of hepatitis C in children (Schwimmer and Balistreri, 2000). Prevalence of hepatitis C is much lower in children than in adults. In western countries, prevalence rates of childhood hepatitis C vary between 0.1-0.4 per cent (Ruiz-Moreno, Leal-Orozco and Millan, 1999). Previously, blood transfusions represented the greatest risk factor for paediatric hepatitis C, but vertical transmission appears to be increasingly the most common source of infection (Aniszewska, Kowalik and Dobosz, 2001; Bortolotti, Resti, Giacchino, Crivellaro et al., 1998). Other sources of childhood infection include non-sterile medical procedures (Chang, 2000), depending on the epidemiology of the virus in any particular geographical area. Overall, hepatitis C infection appears to be milder in children than in adults and often asymptomatic (Jonas, 2001; Lacaille, 2002; Rojahn and Wathne, 2002; Rouassant S, 2002), with liver damage occurring at a slower rate (Hoshiyama, Kimura, Fujisawa, Kage et al., 2000; Jonas, 2001; Resti, Azzari and Bortolotti, 2002). Some authors, however, highlight the potential for future liver damage given the possible degenerative nature of the virus and the lack of longitudinal studies among children (Jara, Resti, Hierro, Giacchino et al., 2003) (Birnbaum, Shneider and Moy, 2000; Bortolotti, 1999; Karim, Alex, Smith and Hardikar, 2000). Also, it has been highlighted that childhood hepatitis C can sometimes take an aggressive course and the factors influencing this are as yet unknown (Jonas, 2002). More severe cases of childhood hepatitis C appear to be associated with concurrent health problems such as HIV, thalassemia and cancer (Resti et al., 2002; Ruiz-Moreno et al., 1999). Given these concerns, there are some arguments for the treatment of hepatitis C among children. Children are rarely included in clinical trials of Interferon and Ribavirin and as such there have been few adequate clinical trials on which
to base any conclusive evidence of the success of treatment in paediatric populations, nor the long term side effects of the drugs used in such treatments.

**Routes of infection**

Hepatitis C is a blood borne virus, which means there has to be blood-to-blood contact for transmission to occur. The main sources of infection include: IDU (through direct sharing of needles and syringes or indirect sharing of other injecting equipment); blood transfusions; other nosocomial infections (within a hospital setting) such as needle stick accidents, non-sterile medical and dental procedures; and non-sterile tattooing and piercing. Pre-1990 up to 10 per cent of new infections of hepatitis C were thought to have been through blood transfusions (Commonwealth of Australia and Australian Institute for Primary Care, 2001). From 1990 the risk of hepatitis C transmission through blood transfusion was greatly reduced to negligible levels through the screening of blood products in developed countries (Schreiber, Busch, Kleinman and Korelitz, 1996), and the exclusion of people with risk factors for blood borne viruses donating blood and body tissue (MacDonald, Crofts, Wodak and Kaldor, 2001). The risk of acquiring hepatitis C through medical blood products is now considered negligible (Dore et al., 2003; Higuchi, Tanaka and Kiyosawa, 2002). The risk of sexual transmission of hepatitis C is considered to be very small (Dore, 2003; MacDonald et al., 2001) and hence it is not classified as a sexually transmitted infection in Australia (Commonwealth of Australia and Australian Institute for Primary Care, 2001; Yatsuhashi and Yano, 2000); this is addressed in more detail later in the thesis. There is a risk of vertical transmission of hepatitis C from mother to baby. Vertical transmission is generally assumed to occur during birth, rather than during

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5 Hepatitis C is, however, considered to be a sexually transmissible infection in the USA based upon American data (Alter, Kruszon-Moran, Nainan, McQuillan et al., 1999).
gestation or breastfeeding (Batallan, Faucher, Poncelet, Demaria et al., 2003; Gibb, Goodall, Dunn, Healy et al., 2000). Estimations of the risk of vertical transmission of hepatitis C are highly variable and are discussed in detail in chapter two. Throughout this thesis, the risk of vertical transmission of hepatitis C is assumed to be around six per cent (Dore, Kaldor and McCaughan, 1997; MacDonald et al., 2001). The risk of transmission through other routes, such as household transmission, is presumed to be very low (Commonwealth of Australia and Australian Institute for Primary Care, 2001). Sharing household items such as razor blades and toothbrushes (on which there may be traces of infected blood) are believed to present a very low risk of transmission (Commonwealth of Australia and Australian Institute for Primary Care, 2001).

The epidemiology of hepatitis C

The World Health Organization (1999) estimates global hepatitis C prevalence to be about three per cent, although prevalence rates vary enormously across regions and countries. The primary routes of infection and characteristics of those infected also vary by region. Wasley and Alter (2000) describe three distinct patterns of hepatitis C epidemiology. In the first pattern, based on the experience of countries such as Australia and the USA, the greatest risks for infection were in the recent past. Italy and Japan represent another pattern of hepatitis C infection, where most cases are among older persons, but the risk of transmission appears to have been in the more distant past. In contrast, Egypt demonstrates a third pattern, where infections are increasing, indicating that the risk factors remain present. IDU is the most important risk factor in hepatitis C infection in Italy (Bortolotti, Crivellaro, Carretta, Tagger et al., 1994; Quaglio, Lugoboni, Pajusco, Sarti et al., 2003). Other sources of infection, including contaminated blood supplies, are more significant risk factors in Italy than in countries such as Australia (La Torre, De Vito,
Langiano, Petta et al., 2003). Wasley and Alter’s (2000) classification is perhaps overly simplified, and in developing countries the epidemiology of the virus has not yet been adequately explored (Crofts, 2001).

It is estimated that there were approximately 225,000 people living with hepatitis C infection in Australia in 2002, with 15,953 diagnoses in the same year (NCHECR, 2003). Hepatitis C prevalence in antenatal samples is often used as an indicator of hepatitis C prevalence in the general population and is usually around one per cent (Spencer, Tibbits, Tippet, Mead et al., 2003). Antenatal samples may produce over-estimates of hepatitis C prevalence as most infections are among people of childbearing age and fertility rates among injectors have been reported to be higher than in the general population (Weber, Tyndall, Spittal, Li et al., 2003). Additionally, the epidemiology of hepatitis C among women is different to that of men, meaning that results for antenatal populations may only be representative of female populations.

More than 75 per cent of people diagnosed with newly acquired hepatitis C reported a history of IDU (NCHECR, 2003). In Australia approximately 80 per cent of all hepatitis C infections are believed to be through IDU (Dore et al., 2003; Garner, Gaughwin, Dodding and Willson, 1997; Law, 1999; Selvey, Lush, Mistry, Sheridan et al., 1996; Sladden, Hickey, Dunn and Beard, 1997). Other studies have indicated the proportion of infections attributable to IDU was actually even higher at 90 per cent (Andrews and Curran, 1996; Copland, 2002). It has, however, been highlighted that injectors may be more likely to be retested for hepatitis C more frequently than the general population, thus inflating the number of recorded cases (ANCAHRD, 2002; Dore et al., 2003; Spencer, Dore, Robotin, Correll et al., 2002; Spencer et al., 2003). Since the risk of transmission through blood transfusions was dramatically reduced from 1990 following the introduction of screening of
blood products, the proportion of new hepatitis C infections through IDU has increased. Among IDU populations, very high prevalence of hepatitis C has been almost uniformly recorded (Hocking, Crofts, Aitken and MacDonald, 2001), ranging from 50 to 70 per cent since the early 1970s (ANCAHRD, 2002). The risk of hepatitis C infection increases with duration of injecting (Crofts, Jolley, Kaldor and van Beek, 1997; Hocking et al., 2001). However, there exists a high risk of infection with only short durations of injecting (Australian Institute of Health and Welfare, 2002). Hepatitis C prevalence among injectors reporting having commenced injecting only in the last three years was 17 per cent in 1998 and rose to 38 per cent in 2002 (NCHECR, 2003).

The majority (65 per cent) of Australian hepatitis C notifications are among young adults, aged 20-39 years (ANCAHRD, 2002), and is thus predominantly prevalent among people in their childbearing years. Approximately 35 per cent of hepatitis C notifications are in females (NCHECR, 2003). There were more female than male diagnoses among the 15-19 years age group in 2002 and 2001 (NCHECR, 2003), but for most other age groups, there were more male than female hepatitis C diagnoses. This was not the case in previous years, in which male and female infections in this age group were very similar and male infections exceeded female infections. If infection rates among young women continue to rise, this may indicate a worrisome trend for young women.

Hepatitis C prevalence is very high in prisons (Butler, 1997; Crofts, 1997; Western Australian Department of Justice, 2002) at about 36 per cent in Australia (Butler, 1997) and is particularly high in female prisons (Butler, Spencer, Cui, Vickery et al., 1999). Of prisoners who were injectors, 90 per cent of female and 66 per cent of male prisoners tested positive for hepatitis C antibodies (Butler et al., 1999). A high risk of hepatitis C infection has been found to be associated with injecting whilst in prison (Hocking et al.,
This gender difference is likely explained because most incarcerated women have been convicted of drug-related offences. These very high hepatitis C prevalence levels are worsened by the lack of clean injecting equipment in prisons (Crofts, 1997). Injectors with a prison history exhibited higher prevalence rates of hepatitis C than those who had never been to prison (van Beek, Dwyer, Dore, Luo et al., 1998), corresponding with Crofts’ (1997) claim that there is a greater risk of hepatitis C infection in prisons than in the community.

The hepatitis C epidemic has been compared with the HIV/AIDS epidemic in Australia (Dore and Kaldor, 1996). There are certainly some similarities, but there are also major differences. Hepatitis C has often been associated with HIV/AIDS because there are a number of parallels in the health and social effects of these infections upon individuals. Both are relatively new infectious blood borne viruses, both went undetected for a time, but perhaps most importantly, both affect young adults within marginalised groups of society. In Australia, HIV/AIDS is most prevalent among gay men, while hepatitis C is concentrated among injectors. Both of these viruses lead to chronic health problems, although the symptoms experienced may fluctuate over time and the HIV/AIDS prognosis is undoubtedly more dismal. The associations of the ways in which these viruses are transmitted is the primary cause for stigmatisation and discrimination (ANCAHRD, 2002). In Australia the primary means of HIV infection is through male homosexual intercourse and there are very few cases of HIV infections transmitted through IV drug use (NCHECR, 2003).

Australia has managed to control the spread of HIV/AIDS through successful programs and policies (including educational and needle syringe programs). These campaigns would not have been so effective had there not been a real sense of union amongst the gay
community and sex workers, as well as injectors, who worked against what constituted a threat to their survival as a community (Hulse, 1997). There are currently an estimated 13,120 people living with HIV in Australia (NH
cris, 2003), compared with 225,000 cases of hepatitis C (NH
cris, 2003). In terms of numbers, hepatitis C is a much greater issue for women than HIV because HIV is heavily concentrated among gay men.

Several reasons have been suggested for the inability to control hepatitis C in the way that has been achieved in the case of HIV/AIDS. HIV/AIDS appeared in Australia soon after the virus was identified in the early 1980s. Hepatitis C is believed to have spread among injectors in Australia in the 1970s, almost 20 years before the virus was identified (Dore
and Kaldor, 1996). Hepatitis C is thought to have been introduced into the country in the 1960s by American military personnel on leave from the Vietnam war (Gibson, Degenhardt, Topp, Day et al., 2003; McCoy, 1980). While needle and syringe programs appear to have greatly reduced the number and proportion of HIV infections through IDU, there is no such success story in hepatitis C. Hepatitis C is considerably more infectious than HIV/AIDS (Dore and Kaldor, 1996; MacDonald et al., 2001) and requires only a trace of infected blood for transmission to take place. HIV infection, unlike hepatitis C, cannot survive outside the body and for transmission to occur, requires greater exchange of bodily fluids than hepatitis C. Hepatitis C requires measures additional to those used for HIV/AIDS if it is to be controlled. The strong sense of community that was at the heart of the success of the HIV/AIDS campaign is not as evident among the injecting community. This may be associated with a greater degree of socioeconomic-marginalisation of many injectors.
Living with hepatitis C

Social stigma is a socially discrediting mark, or label of shame or disgrace that usually results in social rejection and discrimination. Hepatitis C is highly stigmatised because it is associated with IDU and is an infectious disease about which most people know very little, creating fear. This stigmatisation and fear leads to discrimination and for some, contributes to their social exclusion. Hepatitis C can impact upon a person’s quality of life through both physiological effects (symptoms) but also, and often more importantly, though the social and psychological affects it often produces, such as rejection, discrimination, low self-esteem and shame.

Tests for hepatitis C test for hepatitis C antibodies, not the virus itself. A test that indicates that a person has hepatitis C antibodies means that they have been exposed to the hepatitis C virus. This is generally used as a good indicator that someone currently has hepatitis C, although it may also mean that they have had the virus in the past and cleared the virus naturally. Direct, more accurate and revealing clinical tests for hepatitis C are generally only used when assessing patients for Interferon treatment (Commonwealth of Australia and Australian Institute for Primary Care, 2001). For the many people living with hepatitis C who do not have PCR tests performed, this is a source of uncertainty and confusion as they may be unsure of whether or not they actually have hepatitis C (Loxley, Davidson, Heale and Sullivan, 2000). Based on this, they may make critical decisions based upon misconceptions (Southgate and Weatherall, 2003). Recent policy changes have been made,

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6 Polymerase chain reaction (PCR) test: detects the genetic material of the virus in the blood. It can be used to detect the presence or absence of hepatitis C in the blood; the level of the virus present in the blood (viral load); and the genotype of the virus (Commonwealth of Australia and Australian Institute for Primary Care, 2001).

7 A study is currently underway examining knowledge and understanding of hepatitis C among injectors. The study was conceived in response to findings from a qualitative study of injectors in Kings Cross, which indicated injectors are very confused about hepatitis C, particularly the clinical markers used to assess their condition by medical professionals (Southgate and Weatherall, 2003).
however. The National Hepatitis C Testing Policy recommends further diagnostic testing for those who test positive for hepatitis C antibodies (National Hepatitis C Testing Policy Steering Committee, 2003). This committee highlights, however, that in order for this to be feasible, changes are also required in Medicare Benefits Schedule. Recent policy changes aim to make PCR testing available to all people with hepatitis C, regardless of the purpose of this testing, or having had LFTs performed over three months, as has been the case (Hepatitis C Council NSW, 2004).

**Treating hepatitis C**

Treatment is available for hepatitis C infection. Clinical trials continue to refine the treatments for hepatitis C and the general outlook is improving. Interferon is used in combination with Ribavirin as the standard therapy now offered in Australia to treat chronic hepatitis C infection (Commonwealth of Australia and Australian Institute for Primary Care, 2001). Interferon or combination therapy is not effective for everyone and until recently has not been available to current injectors, who represent the largest proportion of people living with hepatitis C. Additionally, the side effects associated with Interferon and combination treatments are severe and intolerable for some people and can cause or worsen depression (Smith, 2003). The efficacy of treatment in achieving a sustained virological response depends upon: the genotype of hepatitis C (there are four genotypes) (Trepo, 2000); stage of liver damage (people with advanced liver disease do not respond as well as those with only early stage damage); viral load (the lower the amount of virus in the blood, the more likely treatment will be successful); age (younger people

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8 In 2002 approximately 1640 people were prescribed Ribavirin and Interferon combination treatment for hepatitis C (NCHECR, 2003).

9 Sustained virological response: when the virus remains below a specified level or undetectable in the blood for a specified period of time.
respond better to treatment); and sex (women respond better to treatment than men) (Commonwealth of Australia and Australian Institute for Primary Care, 2001). Overall, the success rate of combination therapy is about 40 per cent\(^\text{10}\) (Commonwealth of Australia and Australian Institute for Primary Care, 2001; Larson and Carithers, 2001). New evidence suggests that treatment for hepatitis C is more effective in acute and newly acquired infections (Jaeckel, Cornberg, Wedemeyer, Santantonio et al., 2001; Nomura, Sou, Tanimoto, Nagahama et al., 2004).

Quality of life among people with hepatitis C has been shown to reduce during treatment (Bianchi, Loguerio, Sgarbi, Abbiati et al., 2000; Foster, 1999), and increase post treatment with a sustained virological response (Bernstein et al., 2002; Bonkovsky and Woolley, 1999; Neary, Cort, Bayliss and Ware, 1999; Ware, Bayliss, Mannocchia and Davis, 1999). This indicates that the physiological aspects of the virus (which can be reduced through Interferon treatment) do have a significant impact upon quality of life, adding evidence towards the argument for antiviral treatment of the virus. Decisions about beginning treatment must also take into consideration the frequency and severity of symptoms as well as quality of life during and after treatment (Foster, 1999). Other aspects of living with hepatitis C are discussed in detail in chapter two.

\(^{10}\) In patients treated with Interferon only, treatment was reported to be successful in less than 10 per cent of patients (Higuchi et al., 2002). Treatment is considered successful if a sustained virological response is achieved. Bernstein et al. (2002) found that patients had higher quality of life scores during pegalated (slow release) Interferon treatment.
Aims of the thesis

The principle aim of this thesis is to explore the ways in which living with hepatitis C affects childbearing decisions and experiences of motherhood. Existing theories of deviance and stigma and the social construction of motherhood are examined to assess their potential in explaining the issues highlighted in the data.

The multiple realities of women living with hepatitis C in relation to childbearing and motherhood are presented. Common themes and patterns are explored and relatively stable, socially constructed relationships identified. In order to present the multiple realities of these women, the issues they describe are presented from their own perspective and in their own words where possible. Thick, descriptive contextual data from semi-structured interviews is used to explore these issues. This is done using a sample of 34 women with chronic hepatitis C in Sydney, using semi-structured interviews and a brief questionnaire.

In order to meet these aims, three separate issues are explored at length throughout the thesis: the social experience of women with hepatitis C, childbearing decisions and hepatitis C, and the meaning of motherhood for women living with hepatitis C.

Significance of the research aims

Australian women now have more choice regarding their reproductive health than ever before. They have varying degrees of control over when, how many, how, or if at all, they have children. This has been possible though both technological advancements and major social changes (Albury, 1999; Gillespie, 2001). In particular, it has become more socially acceptable to remain childless (Cannold, 2000; Gillespie, 2001; Hird and Abshoff, 2001).
However, just as there are social controls over which women are considered suitable for motherhood, there are also conditions under which it is, and is not, acceptable to remain childless (Lawler, 1996). Most women who have chosen to remain childless in Australia are of higher SES (Gillespie, 2001) and have alternative legitimate social roles to motherhood (Marshall, 1993).

It has been demonstrated above that hepatitis C is a growing problem in Australia, particularly for adults of childbearing age. Recent data indicates that new female infections are now outnumbering new male hepatitis C infections in young age groups, signalling that hepatitis C may be an increasing problem for women of childbearing age. The long lag time from hepatitis C infection to serious disease means that the burden of disease of the epidemic is expected to grow considerably in coming decades as prevalence and incidence continue to rise.

Hepatitis C affects women of largely childbearing age, and is a growing problem in Australia, as prevalence and incidence rates continue to rise. This thesis aims to identify the ways in which hepatitis C affects childbearing decisions and motherhood and in doing so addresses a major and growing contemporary social issue. While hepatitis C prevalence and incidence monitoring systems are now in place and medical treatments continue to improve, there is little social understanding of hepatitis C (Hopwood and Southgate, 2003).

Goffman (1963) defines ‘social identity’ as the social category into which an individual is assumed to fit and attributes that they are assumed to possess. An individual’s ‘actual social identity’ is the category into which they can be proven to fit and attributes that they can be proven to possess. The social labels that are applied to individuals or groups of people are indicators of their actual social identity. Motherhood remains central to the female social identity (Albury, 1999; Blyth and Moore, 2001; Crouch and Manderson, 1993; Hird and
Abshoff, 2001; Ireland, 1993; Lawler, 1996; Morell, 2000; Rich, 1984; Williams, 2004; Woollett, 1991). This thesis seeks to establish what effects hepatitis C has upon childbearing decisions and experiences of motherhood. If these effects are significant, then this may present considerable social issues which should then be addressed through policy change.

Existing studies on the social aspects of hepatitis C

When research for this thesis began, there was very little existing literature on the social effects of living with hepatitis C. During the three and a half years that it has taken to complete this study, several research papers have been published on the social environment of people living with hepatitis C and importantly, some of these have considered the role of gender in determining the social experience of living with hepatitis C (Banwell, Bammer, Main, Gifford et al., 2003; Crockett and Gifford, no date; Gifford et al., 2003; Gifford, O'Brien, Smith, Temple-Smith et al., Forthcoming; Hopwood and Southgate, 2003; Platt and Gifford, 2003; Temple-Smith, Gifford and Stoove, 2004). Throughout the thesis, this literature is examined in relation to the findings from the interview data collected for this study.

As highlighted above, there are several similarities between the hepatitis C and HIV/AIDS epidemics in Australia, certainly with regards to the social meanings associated with these viruses. It was anticipated that there would be some parallels between the effects that living with hepatitis C has upon childbearing and motherhood, and the effects of living with HIV/AIDS. At the commencement of this thesis there was some existing literature on the ways that HIV/AIDS can influence childbearing decisions. This literature was used to guide refinement of the research question.
The evolution of the research question

When this study was begun, the research question was focussed upon the impact of hepatitis C upon childbearing decisions among women living with hepatitis C. During early interviews, it became apparent that although certainly relevant, the issue of the impact of hepatitis C upon childbearing decisions was only a component of a larger social issue, and as such the research question was broadened. It is often the case in iterative qualitative research that the initial research question may change and this demonstrates one of the benefits of a flexible qualitative approach in ensuring relevant, quality research (Britten, 1995; Hudelson, 1994).

The social meanings given to motherhood among women with hepatitis C, particularly in relation to their social identity, appeared to be of much greater importance than the timing and parity of children. The social meaning of motherhood, and other social processes, such as stigmatisation, contextualised childbearing decisions. The aims of the research were extended to permit the rich contextualisation of childbearing decisions, and included examination of women’s social experience of hepatitis C, and the meaning of motherhood. Much of the thesis does address the initial research question of the impact of hepatitis C on childbearing decisions. However, this is set within a broader research question that addresses the effects of hepatitis C upon women’s social identity through the process of stigmatisation.

The following chapters review existing literature on women and hepatitis C, gender and IDU, and the theoretical perspectives (deviance and stigma and the social construction of motherhood) that are examined for their potential to explain the social issues and processes that emerged from the interview data.
Women’s experience of health and illness differs to that of men. Women experience different kinds of disease as well as having different social experiences of diseases (Broom, 1989; Miles, 1991). Women experience more illness and consult medical professionals more frequently than men (Macran, Clarke and Joshi, 1996). Women’s health is also determined by the health services available to them and the way that they are treated within the health care system (Broom, 1998a; Broom, 1998b; Gijsbers Van Wijk, Van Vliet and Kolk, 1996). Women have different health care needs to men (Gijsbers Van Wijk et al., 1996), in particular, women’s reproductive health needs result in greater contact with health professionals than men (Hardey, 1998), although this does not explain their higher levels of illness and treatment seeking (Broom, 1998b; Miles, 1991). Several alternate explanations for these differences have been offered: statistical artefacts, genetic differences between the sexes and social or cultural differences (Hardey, 1998; Miles, 1991). One explanation for higher rates of poor health among women is that they are more likely to report health problems than are men (Broom, 1989). Macintyre et al (1999), however, found no gender differences in the initial reporting of conditions, nor any evidence that women were more likely to report ‘trivial’ conditions.

More recent research indicates that gendered health inequalities are far more complex than commonly thought (Denton, Prus and Walters, 2004; Hunt and Annandale, 1999; Macintyre et al., 1999; Macintyre, Hunt and Sweeting, 1996; McDonough and Walters, 2001). Bird and Rieker (1999) argue that most research assumes that health inequalities are either biologically or socially determined when in fact they are produced through a combination of biological differences coupled with social processes, which is altogether
more complicated. It has been widely believed that women experience more poor health than men but men die earlier than women. Macintyre et al (1996), however, found that gendered health differences actually vary by the symptom or condition, and according to stages of the life cycle. Denton et al (2004) found that structural (SES, age, social support) and psychosocial (critical life events, stress, psychological resources) determinants of health are generally more important for women, while behavioural health determinants are generally more important for men. Similarly, McDonough and Walters (2001) found women reported more distress and chronic conditions than men but men experienced more illness as a result of heavy drinking.

Gijsbers Van Wijk (1996) suggests that women’s health inequalities are a consequence of the basic inequality that exists between men and women. Closely related to this argument, Anson, Paran, Neumann and Chernichovsky (1993) suggest that women’s social roles are the major cause of gendered health inequalities. It has been argued that whether or not women are mothers can contribute to their health because motherhood interacts with income, availability of health insurance, and availability of social and financial support (Bernstein, 2001). Others have, however, found this relationship to be more complex and found that lone mothers in full time employment had poorer psychosocial health than other mothers (Macran et al., 1996). Interestingly, recent research suggests that gender roles also have a negative impact upon men’s health (Courtenay, 2000; Gannon, Glover and Abel, 2004).

Building upon the gender role argument, it has been argued that because women often have multiple roles; wife, mother and employee, this is likely to contribute towards poorer health because of the increased stresses placed upon them through these roles (Anson et al., 1993). Conversely, Janzen and Muhajarine (2003) found that women with three roles
(employee, wife and motherhood), rather than only one or two roles, were less likely to report illness, which conflicts with the theory that more social roles will result in more illness. These results must be interpreted with caution, however. To be able to maintain multiple roles requires a certain degree of health. Yet at the same time, women of lower SES may not have the luxury of choosing how many roles they play. For example, if a woman with poor health is also a mother, despite her poor health, she may be forced to work in order to maintain a reasonable standard of living for her children and herself. These multiple roles may well have an impact on her health.

There are health differences among women, based upon their SES (Arber, 1997; Macran et al., 1996), as there are among men (Courtenay, 2000). Matthews (1999) reported that although there are differences in the effects that SES factors have upon men and women’s health, the causes of inequality appear to be similar for men and women. These causes of inequality include ethnicity, occupation, paid employment, income and domestic labour. For example, in the USA, Zierler and Krieger (1997) report that differences in women’s risk of HIV infection is influenced by their SES, and race in particular.

While the gendered differences in mortality and morbidity require further exploration, it seems sensible to assume that women’s experiences of living with hepatitis C will be different to men’s, for both biological and social reasons. Hepatitis C has several sociological implications, and the experience of living with hepatitis C varies within and between different social groups, women being one of these groups (Hopwood and Southgate, 2003). The lives of women, as mothers or potential mothers in particular, are affected by hepatitis C differently to men (Richmond, 1999; Thomas, 1999). Temple-Smith et al (2003) assessed the differences in the lived experiences of women and men with hepatitis C in Australia and found there to be three key gender-related differences. Firstly,
women were more likely to seek help with their hepatitis C, whereas men tended to downplay their status and avoided health care. Secondly, women expressed a need for support, information and health care but men denied having such needs. Thirdly, women reported experiencing judgemental attitudes and for these to have negative impacts upon them. Men also reported being treated differently because they have hepatitis C, but were able to dismiss such events. Based on this qualitative data, it seems women experience more negative effects of stigma associated with hepatitis C than men. Day (2004; 2003) reported that women are more likely to report hepatitis C related discrimination than are men. Overall, Temple-Smith et al (2003) found that ‘gender influences men’s and women’s experiences of hepatitis C and shapes the way they respond to diagnosis, social support, information and health care’. This section will examine the characteristics of women living with hepatitis C in Australia and how their experience of living with the virus differs from that of men.

**Sex ratio of infections**

In Australia in 1998-2002, there was a male to female sex ratio of hepatitis C infections of approximately 1.7:1 (NCHECR, 2003). This sex ratio is likely to be because the primary route of hepatitis C infection is IDU, and there are typically twice as many male injectors than female injectors in Australia (Day and Dolan, 2002; Loxley, Carruthers and Bevan, 1995). Within IDU populations, however, in 2002 there were greater proportions of women who tested positive for hepatitis C antibodies than men in all but the oldest age groups (NCHECR, 2003), indicating that among injectors, women are at greater risk of acquiring hepatitis C. Data on diagnoses of hepatitis C infection in 2002 indicate that in younger age groups there are now more women than men becoming infected with hepatitis C. While there is a significant sex ratio of men infected with hepatitis C than women, this
gap may be closing according to recent figures (NCHECR, 2003), indicating that hepatitis C will be a growing problem for women. Additionally, Day and Dolan (no date) report that women are tested for hepatitis C more frequently than men, which may mean that they have more contact with hepatitis C related health services than men, which could inflate women’s prevalence rates.

The prevalence of hepatitis C among pregnant women is variable but does appear to be increasing (Healy, Cafferkey, Conroy, Dooley et al., 2000). Within an Australian sample, 1.1 per cent were infected (Garner et al., 1997), and in a British sample, prevalence was low at 0.19-0.22 per cent (Ades, Parker, Walker, Cubitt et al., 2000); and 0.6 per cent in a Scottish sample (Goldberg, McIntyre, Smith, Appleyard et al., 2001). Prevalence was higher within a Greek sample at 1.95 per cent (Raptopoulou-Gigi, Orphanou, Lalla, Lita et al., 2001). Among injecting drug-using women, however, prevalence is very high. Latt et al (2000) reported that of 131 pregnant women injectors in Sydney, 125 (over 95 per cent) tested positive for hepatitis C antibodies. In Australia, general antenatal populations exhibit prevalence of just over one per cent (ANCAHRD, 2002; Spencer et al., 2003). As most injecting women (and men) are of childbearing age (ANCAHRD, 2002), these high prevalence rates are concerning.

**Characteristics of women with chronic hepatitis C**

There is a lack of data describing the socioeconomic characteristics among people living with hepatitis C that goes beyond detailing their age, sex and IDU. As most hepatitis C infections are through IDU, it would be helpful to look at the characteristics of IDU populations. However, the characteristics of IDU populations cannot be fully delineated because of the underground nature of illicit drug use and so there exists some degree of
bias in all IDU population samples (Hocking et al., 2001). Hence, this discussion of how women with hepatitis C compare with contemporary society is somewhat limited because of the lack of data. The data collected for this thesis, detailed in subsequent chapters, provides some insight into the socioeconomic conditions of some women with hepatitis C. Given the small sample size of this study and the qualitative nature of the data on which this thesis is based, it is not possible to make direct comparisons with quantitative data that exists on many aspects of Australian social and economic characteristics.

A recent large-scale study of Australian women living with hepatitis C (WLHC) (Gifford et al., 2003) provides some indicators of the social marginalisation of many of these women, based upon their sample characteristics. It is difficult to assess the representativeness of the sample because of the lack of demographic data recorded in notification data. The survey was a self-administered questionnaire of a non-clinical sample of women living in Victoria and the ACT. In accessing non-clinical populations using hepatitis C newsletters and a questionnaire mail out using state Hepatitis C Council NSW mailing lists, the sample included a broader range of people living with hepatitis C than most samples. The majority of people living with hepatitis C do not receive specialist care. This is related to the fact that treatment for hepatitis C has not been available to current injectors until very recently (Gifford et al., 2003), which thus excludes many people living with the virus.

Given the high prevalence of the virus among injectors (ANCAHRD, 2002), and low prevalence in the general population, it seems relatively safe to assume that most people

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11 Throughout this thesis, this study is referred to as the WLHC (Women Living with Hepatitis C) sample.
12 The Hepatitis C Council NSW is an independent, charitable, community-based organisation, primarily funded by the NSW Health department. Their roles include: providing assistance to people affected by hepatitis C; running a hepatitis C helpline; providing hepatitis C education; publishing hepatitis C information; producing and circulating the Hep C Review; undertaking community activities in the interest of hepatitis C affected communities; maintaining a website on hepatitis C related issues; liaising with key organisations and individuals; playing a central role in the Australian Hepatitis C Council.
with hepatitis C share similar characteristics to injectors in general. When compared to samples of injectors and considering the epidemiology of the virus, the WLHC sample (Gifford et al., 2003) appears to be a good representation of women with hepatitis C in Australia.

Of the 462 women who responded, (with a response rate of 75 per cent) 59 per cent were dependent on social security benefits, indicating low SES amongst this group. Most (86 per cent) were born in Australia and more than half were described as being ‘educationally or economically disadvantaged’ (Gifford et al., 2003). The sample had a mean age of 35 years, and 34 per cent reported to be living in households with dependent children. Given the high rates of IDU among these women (83 per cent were current or past injectors), it may be suggested that a greater proportion of them had indeed born children, but they did not have them in their custody for reasons primarily linked to their IDU. A recent review in London of 290 cases of childcare concerns found that 34 per cent involved parental drug or alcohol problems (Advisory Council on the Misuse of Drugs, 2003). The same investigation found that in England and Wales, only 37 per cent of fathers and 64 per cent of mothers with ‘serious drug problems’ were still living with their children. Similar associations between child abuse and neglect and parental drug and alcohol use have been established in Australia (Tomison, 2002). Most hepatitis C infections in Australia are among current and past injectors (80 per cent) (ANCAHRD, 2002). As such, the high proportion of the sample (83 per cent) who were current or past injectors can be assumed to be representative of people in Australia with hepatitis C.
Education levels among the WLHC sample (Gifford et al., 2003) were low, with 65 per cent not having competed secondary school (year 12). Within the Australian population, approximately 30 per cent of people aged 20-44 had not completed secondary school (year 12) in 2001, (Australian Bureau of Statistics, 2002b), and so the educational attainment of these women is significantly below the Australian standard. Additionally, using a standardised measure, the SF-12 (Ware, Kosinski and Keller, 1996), Gifford et al (2003) found that women with hepatitis C had higher levels of physical and mental health problems than Australian norms when compared with the results of the Australian National Health Survey (1995), as do injectors in general (Adhikari and Summerill, 2000).

Only a small proportion of the WLHC sample (17 per cent) had received any hepatitis C specific treatment (Interferon or combination therapy), and half of these women were aged 40-49 (Gifford et al., 2003). The proportion of the sample who had received treatment for hepatitis C is higher than we would expect, as only a very small proportion of people living with the virus have been treated with Interferon. At the end of the 1990s less than 10,000 people with hepatitis C had been treated with Interferon, which is about 5 per cent of the estimated number of people living with the virus (Lin, Barker and Batey, 1999).

All of these characteristics indicate that a high proportion of this group of women generally live on the fringe of Australian society. The varying features of social disadvantage detailed above combine to compound and maintain their disadvantage. For example, there may be a strong relationship between their poor health status and their low SES, as has been concluded for general populations (Feinstein, 1993; Germov, 1998; Kawachi and Kennedy, 1997; Link and Phelan, 1995). Although women’s participation in the labour force has

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13 The minimum school leaving age in Australia is 16 years (year 10).
increased in Australia, that 59 per cent of the above sample are dependent on social security benefits indicates that this trend in increasing employment opportunities may not be open to this group of women, and that in fact they are marginalised. That they are not employed implies that they may be able to provide the ‘intensive mothering’ that is so highly valued in contemporary society. That said, within contemporary industrialised societies, women are often dependent on men and/or the state (and often others), particularly so once they become mothers, as their capacity to work for financial and social autonomy is restricted (Crouch and Manderson, 1993; Oakley, 1979a).

As detailed above, many women with hepatitis C are dependent on social security benefits. The poor educational attainment levels among women with hepatitis C may be contributory to this high rate of state benefit dependency. By having children and being more vulnerable to remaining on state benefits they fall deeper into dependency, reducing their capacity to break free from it.

Most women with hepatitis C are likely to be socially disadvantaged and have limited access to services, technologies and support for alternative forms of family formation. The single mother has become a common feature of contemporary western society, and although it is far from being perceived as an ideal situation, there is some degree of acceptance of this form of motherhood (Crouch and Manderson, 1993; McDonald, 2003). For the single mother with hepatitis C though, along with her other negative character traits, the status of single mother could be used as one of many ways to discount her and her mothering abilities. Additionally, her other characteristics and even achievements may also be brought into question more so than the single mother who does not have hepatitis C.
Gender specific issues of hepatitis C

There are several aspects of living with hepatitis C in which women experience distinct differences from men. In particular, the ways in which hepatitis C may affect the reproductive health of women is a major concern. Women with hepatitis C have concerns regarding vertical transmission (Temple-Smith et al., 2003), as well as the potential effects of pregnancy upon the progression of hepatitis C related disease; (studies have indicated that pregnancy can in fact be beneficial in women with hepatitis C, (Hadzic, 2001)). Although the risk of sexual transmission is of concern to both women and men, gendered power relations may mean this is of greater concern to women, as is the case in HIV/AIDS (Day and Dolan, 2002).

The risk of vertical transmission of hepatitis C

The available data on the risk of vertical transmission of hepatitis C is limited because of small sample sizes, incomparable samples, poor follow-up and varying clinical criteria. In a review of hepatitis C in pregnancy, Hunt et al (1997) found that reports of the vertical transmission rate varied from six to 36 per cent (Ceci, Margiotta, Marello, Francavilla et al., 2001; Gibb et al., 2000; Hillemanns, Dannecker, Kimmig and Hasbargen, 2000; Michielson and Van Damme, 1999; Ohto, Terazawa, Sasaki, Sasaki et al., 1994; Okamoto, Nagata, Murakami, Kaji et al., 2000; Resti, Azzari, Mannelli, Moriondo et al., 1998; Spencer, Latt, Beeby, Collins et al., 1997). Although variable, the data that exist indicate that the risk of vertical transmission of hepatitis C is reasonably low (although the acceptability of this risk may be perceived very differently). Also, there is no evidence to suggest that maternal hepatitis C is associated with increased risk of congenital malformations, stillbirths, or

14 Temple-Smith et al (2003) found that for both women and men, the risk of vertical transmission to their children was their greatest concern regrading hepatitis C.
intrauterine malnutrition (Bader, 1995; Hadzic, 2001). Evidence indicates that the risk of vertical transmission of hepatitis C is not associated with parity or duration of infection (Resti, Bortolotti, Azzari, Giacchino et al., 2000). Several risk factors have, however, been identified in increased risk of vertical transmission: co-infection with HIV (European Paediatric Hepatitis C Virus Network, 2001; Mazza, Ravaggi, Rodella, Padula et al., 1998; Thomas, Villano, Riester, Hershow et al., 1998); maternal viral load (Giacchino, Tasso, Timtilli, Castagnola et al., 1998; Michielson and Van Damme, 1999; Pilla and Zucker, 2001; Spencer et al., 1997; Vincenzo, Fillipo, Laura and Marcello, 2003); and acquiring hepatitis C during pregnancy (Hunt et al., 1997). Among women in whom there is no detectable hepatitis C RNA (virus), the risk of vertical transmission is very low, or zero (Okamoto et al., 2000).

**Antenatal screening**

Medical professionals remain divided on whether or not to routinely screen for hepatitis C during pregnancy. Some argue that routine antenatal hepatitis C screening is inefficient because of low prevalence rates, and that there is little to be gained through identifying hepatitis C infection during pregnancy and so does not warrant universal screening. It remains largely unknown which women are more likely to transmit the virus to their child, and unlike HIV, there are no effective treatments that could be offered during pregnancy (Zein, 1997). Nevertheless, others recommend that women with risk factors for hepatitis C, such as IDU, are screened (Burns and Minkoff, 1999). In Australia, testing policies for hepatitis C during pregnancy are widely varied (Giles, Sasadeusz, Garland, Grover et al., 2004; Spencer et al., 2003). Additionally, despite the differences in the risk of vertical transmission and availability of treatments during pregnancy to reduce this risk, testing policies for hepatitis C were found to be similar to those for HIV (Spencer et al., 2003).
Risk of transmission via breastfeeding

Breastfeeding is an important element of motherhood for many women. In fact, breastfeeding is often cited as a justification of the gendered division of labour, in that women are biologically designed to bear and feed babies (Palmer, 1998). The benefits of breastfeeding for both mother and baby have been clearly identified, and mothers are strongly encouraged to breastfeed, although there is little social support to allow them to do so. Studies have so far been inconclusive as to whether breastfeeding is a risk factor in vertical transmission of hepatitis C (Dhoherty, 1993; Ruiz-Extremera, Salmeron, Torres, De Rueda et al., 2000; Voyer, Nobre and JF, 2001). One study was able to identify certain conditions in which breastfeeding may be a risk factor, (European Paediatric Hepatitis C Virus Network, 2001). This study concluded, however, that breastfeeding among women with hepatitis C should not be discouraged as long as they are not HIV-infected. Others claim that the risks associated with transmission through breastfeeding depend upon the mother's hepatitis C viral load (Kumar and Shahul, 1998). Current opinion is that the benefits of breastfeeding far outweigh any risk of virus transmission, and as such, breastfeeding among women with hepatitis C should not be discouraged (Commonwealth of Australia and Australian Institute for Primary Care, 2001; MacDonald et al., 2001; Pilla and Zucker, 2001; Richmond, 1999). This is based upon a larger number of studies that found breastfeeding and risk of vertical transmission to be unrelated (Hadzic, 2001; Lin, Kao, Hsu, Ni et al., 1995; Pembrey, Tovo and Newell, 2001; Resti, 1999; 1998; Spencer et al., 1997).
Mode of delivery and risk of vertical transmission

It has been suggested that the risk of vertical transmission in utero is minimal and that the greatest risk occurs at or around the time of delivery (Batallan et al., 2003; Gibb et al., 2000). Other research indicates that transmission may in fact occur in utero (Giorlandino, Gambuzza and Di'alesio, 1995). It may be possible that caesarean section may reduce the risk of vertical transmission but there remains controversy over whether this is the case. Evidence suggests that caesarean sections performed before the onset of labour can reduce the risk of vertical transmission (Okamoto et al., 2000), but no studies had sufficient power to produce statistically significant results (Pilla and Zucker, 2001). Other studies have found no evidence of elective caesarean being beneficial in reducing vertical transmission (MacDonald et al., 2001; Spencer et al., 1997). Because of the scant evidence in its favour, most studies conclude that elective caesarean is not beneficial in preventing the risk of vertical transmission of hepatitis C. However, a German study found that women with hepatitis C were twice as likely to have a caesarean delivery than hepatitis C negative women. They did not find any significant risk factor to explain this increased rate of caesarean section deliveries (Hillemanns et al., 2000).

Sexual transmission of hepatitis C

The risk involved in the sexual transmission of hepatitis C remains contentious. In a review of the evidence, Rooney and Gilson (1998) concluded that there is a ‘small but definite risk of sexual transmission of hepatitis C.’ More recently, an Italian study concluded that the risk of sexual transmission within heterosexual monogamous couples is extremely low, or possibly zero (Vandelli, Renzo, Romano, Tisminetzky et al., 2004). Advice remains
conflicting, however, with some medical professionals recommending the use of condoms among monogamous heterosexual couples, and others not. Vandelli et al (2004) concluded that the use of condoms is not required to prevent sexual transmission of hepatitis C. Some sources advise against intercourse during menstruation or in the presence of genital lesions in order to reduce the risk (Rooney and Gilson, 1998). The Hepatitis C Council of New South Wales highlight that the likelihood of sexual transmission occurring is dependent on whether or not there is blood to blood contact during sex, and thus to reduce the risk, such occasions should be avoided (2002). For women living with hepatitis C, these mixed messages may be confusing, and indirectly influence the likelihood of childbearing by restricting sexual contact in order to reduce the risk of sexual transmission.

**Hormonal and menstrual irregularities and birth control**

Hepatitis C has been reported to present hormonal concerns relating to hormonal and menstrual irregularities for some women. The association between these irregularities is unclear, but it is accepted that chronic ill health can cause such problems (Thomas, 1999). The Hepatitis C Council of Western Australia (1999), however, states clearly that ‘the hepatitis C virus does not affect menstruation or menopause adversely.’

Heroin, methadone and other opiates can suppress the normal female hormonal cycle (Thomas, 1999). Because so many women with hepatitis C are current or past injectors, this is likely to complicate any association between hepatitis C and menstruation. There are also concerns relating to the use of the contraceptive pill, in particular, depression associated with hepatitis C may be worsened by the contraceptive pill (Hepatitis C Council of Western Australia, 1999). Because these drugs are metabolised by the liver, there exist concerns of putting increased strain on a hepatitis C infected liver (Thomas, 1999). The Hepatitis C
Council of Western Australia (1999) reports that ‘unless there is severe liver disease, the pill and hormone replacement can be taken by women who are hepatitis C positive’ but ‘some women and some doctors may feel better about using skin patches or implants for hormone replacement’ which avoid them being processed by the liver.

Women’s concerns about the use of the contraceptive pill, and other hormonal forms of contraception, may influence their probability of becoming pregnant. Banwell et al (2003) found very low levels of contraceptive use among women with hepatitis C. This was not related to drug use status, changes in alcohol consumption since diagnosis, or whether current drug users were in drug treatment. Nor was there any relationship with a range of health, treatment or other variables relating to pregnancy or childcare. Banwell et al (2003) found that women who perceived there to be a very high risk of vertical transmission of hepatitis C or who had decided not to have children for other hepatitis C related risks were no more likely to use contraception. While these women may perceive the risk of vertical transmission occurring to be high, this does not necessarily mean that they perceive it to be unacceptable.

**Natural history of hepatitis C in women**

Although some studies have indicated that women fare better than men in the natural history of the hepatitis C infection, evidence is inconclusive (Dore, 2001), and other studies have found gender to have no effect (Danta et al., 2002). Seeff (2002) reported that spontaneous resolution (naturally clearing) of the virus is more common among young women than young men and cirrhosis (scarring of liver tissue) is slightly less common among young women than young men. Also, Poynard et al (1997) reported men to be more likely to develop fibrosis of the liver. It has been shown that male gender impacts on
health related behaviour and these behaviours impact upon men’s health and mortality rates (Thom, 2003). Health related behaviours such as drinking alcohol have been strongly associated with a poor hepatitis C outcome (Dore, 2001). If men are more resistant to change and less likely to reduce risky behaviours than women, then this may account for any gender differences in the natural history of the virus.\textsuperscript{15}

**Quality of life of women living with chronic hepatitis C**

Lower quality of life scores among people living with hepatitis C have been repeatedly observed using a range of instruments (Conrad, Dunn and Macdonald, 2001). Hepatitis C has been shown to negatively affect quality of life through biological factors causing physiological problems; psychosocial problems; interpersonal and sexual problems; social functioning; work and economic changes and lifestyle changes (Conrad et al., 2001). More specific to women, Gifford et al (2003) found women living with hepatitis C have a lower health related quality of life than the general population.

Rodger et al (1999) demonstrated that the social labelling involved in the diagnosis of the virus contributes towards this reduction in quality of life. Rodger et al (1999) assessed the quality of life of groups of people who were aware that they had hepatitis C and compared quality of life scores with a group who did not know that they had hepatitis C. The group who were aware of their hepatitis C status scored lower than the group who were not aware after controlling for SES, clinical markers and other factors. Miller et al (2001) also found that reduced quality of life associated with hepatitis C is more closely associated with perceived social discrimination than clinical markers.

\textsuperscript{15} Gifford et al (Forthcoming) reported that men with hepatitis C were concerned they would not be able to drink alcohol with their mates because they had the virus. Social drinking with other men is an important part of the Australian male identity.
Lower quality of life has been associated with IDU (Ryan and White, 1996). A study of injectors in Sydney’s Kings Cross found that quality of life scores were lower among injectors who reported testing positive for hepatitis C, than those who did not have hepatitis C (Kimber and Day, 2003), a finding supported by a UK study among a clinical population (Foster, Goldin and Thomas, 1998).

Gifford et al (2003) and Temple-Smith et al (2003) showed that hepatitis C has a significant impact upon many aspects of women’s lives. Their study on women with hepatitis C was followed by a very similar study of men living with hepatitis C (Gifford et al., Forthcoming). Whilst each study shows hepatitis C to have negative impacts upon the lives of all people living with the virus, the ways in which it does this and to what extent, are determined by gendered social roles. For example, women’s primary role remains motherhood, and for men, being an economic provider. Hepatitis C has been shown to impact upon each of these social roles, thus challenging their social identity and quality of life.

**Summary: Women and hepatitis C**

Hepatitis C affects women differently to men. The differences are not purely physiological. Many of the non-physiological impacts of hepatitis C that determine quality of life are rooted in the contemporary gendered organisation of society, that determines women’s and men’s social roles and identities. Hepatitis C can present challenges to these gendered identities and as such can be destructive. Women’s primary social role is centred on mothering, and hepatitis C may present challenges to achieving full motherhood status, determined by the current ideology of motherhood. In a similar way to women with HIV, women with hepatitis C have acquired an infectious and potentially fatal virus, which leads
society to the perception that they have ‘failed in their appropriate roles as carers and nurturers, responsible for the next generation’ (Lawless, Kippax and Crawford, 1996).

There remain many uncertainties surrounding diagnosis, prognosis, treatment, transmission risk factors and the risk of vertical transmission of hepatitis C. Research is conflicting on many of these aspects of hepatitis C, and this leads to confusion among medical professionals, people living with the virus and society. It is unclear what actions and behaviours are appropriate and inappropriate among people living with hepatitis C because the effects of behaviours and decisions are not fully established. Consequently, making decisions regarding hepatitis C, such as childbearing decisions, is made extremely difficult because of conflicting information, advice and expectations.

Just as women’s experiences of living with hepatitis C are different to those of men, so too are their experiences of IDU. The issues that women face as injectors contextualise the social setting in which they experience hepatitis C, make childbearing decisions and give meaning to the role of motherhood. The social contexts in which women inject and ultimately become exposed to hepatitis C are examined in chapter three.
Chapter 3: Gender and Injecting Drug Use

A majority of injectors, both male and female, are unemployed, have low educational levels and are from low socioeconomic backgrounds (Loxley et al., 1995; McAllister and Makkai, 2001; Mullings, Marquart and Diamond, 2001). Most injectors are in their 20s and 30s (McAllister and Makkai, 2001), which are the key childbearing years, and as such this presents significant social problems.

Although there are many parallels, women’s experiences and problems associated with IDU are different to those of men. Some of these issues are specific to women injectors, but mostly these surround women’s drug use in general. Women drug users, especially injectors, are considered to be more deviant, and less socially acceptable than men (Barnard, 1993; Broom, 1994; Copeland and Hall, 1992; Dwyer, Richardson, Ross, Wodak et al., 1994; Ettorre, 1994; Goldberg, 1995; Hunter and Judd, 1998; Mulia, 2000; Rosenbaum, 1981; Taylor, 1993; Vandor, Juliana and Leone, 1991; Wright, 2002). As a result, female drug users are more socially isolated than their male counterparts (Copeland, 1994). This greater perception of deviance may be a matter of numbers; there are roughly two male to every female injector in Australia (Day and Dolan, 2002; Loxley et al., 1995; MacDonald et al., 2001; MacDonald, Wodak, Ali, Crofts et al., 1997; McAllister and Makkai, 2001; Stevens and Wardlow, 1994). It may be that women injectors are perceived as more deviant because fewer of them inject, when compared with men. It is not that women necessarily use less drugs than men, but they are more likely to use legal, rather than illegal substances (Copeland, 1994; Stevens and Wardlow, 1994; Vandor et al., 1991). In fact, throughout history, women’s use of prescribed and other legal drugs has been persistently high (Broom, 1994; Chang, 1994; Galbraith, 1991). As suggested in much of
the literature on gender and drug use, this is because illicit drug use is perceived to be in conflict with the social roles and norms of women. Women’s primary social role is that of carer; of children and men in particular. When women use drugs, it is perceived to restrict their abilities to perform their caring duties, and their other roles as a social stabilizer (Blume, 1990; Broom, 1994; Copeland, 1994; Ettorre, 1994; Lawless et al., 1996; Rosenbaum, 1981). However, some women report that their drug use can actually be beneficial in their mothering (in the short term at least) to help them cope with the responsibilities involved in motherhood (Boyd, 1999; Klee, 2002b; Taylor, 1993; Taylor, 1998).

In recent times, women drug users, particularly injectors, have been perceived as a risk to their children, in utero and throughout childhood. There are several reasons for this. The identification of foetal alcohol syndrome and harms associated with drug use during pregnancy have led to the perception of maternal drug use as a form of child abuse, especially in the USA where the issue has been addressed with a more punitive approach (Beckett, 1995; Keane, 1996; Moss, 1991). Women’s drug and alcohol use in general appears to have become more socially acceptable over time (Lynsky, Day and Hall, 2003). The War on Drugs, particularly in the USA has targeted poor non-white drug-using mothers and adopted a highly punitive approach to the problem (Beckett, 1995). It has been shown that women injectors have higher rates of fertility, although this is likely to be explained by behavioural factors, as it was also found that they have lower rates of contraception than non-injecting women (Weber et al., 2003). Injectors are less likely to be married than non-injectors (McAllister and Makkai, 2001) which may suggest that these women are less likely to be in stable supportive relationships.
It has been found that drug-using women generally attempt to stop or at least reduce their drug use during pregnancy (Deren, Davis, Tortu, Beardsley et al., 1995; Lewis, Klee and Jackson, 1995; Taylor, 1993), indicating that they share similar values to those in the ideology of motherhood and much of the medical profession. However, their circumstances and lack of support often lead them to fail to curtail their drug use during pregnancy, and there is little recognition of these mitigating factors. In the USA there are a disproportionate representation of non-white women and women of low SES who are tested for drug use and prosecuted for various forms of child abuse and neglect as a result (Beckett, 1995; Boyd and Faith, 1999; Goldberg, 1995).

Female drug use is closely associated with criminality in a different way than male drug use is. The majority of crimes that women are convicted of are related to drug use, whereas men are more likely to commit a wider range of crimes, which are often more violent (Byqvist, 1999; Willis and Rushforth, 2003).

Women’s drug use has traditionally been associated with promiscuity and other moral issues, which continues to be the case today (Blume, 1990; Lawless et al., 1996; Mulia, 2000). It has been found that women injectors are more likely to have sex with multiple partners than are non-injecting women (Mullings et al., 2001). In recent decades, sex work has remained closely associated with women’s drug use (Day and Dolan, 2002; Kuhns III, Heide and Silverman, 1992; Rosenbaum, 1981; Vandor et al., 1991). Among female drug users, sex work is perceived as a last resort when they no longer have access to socially acceptable means of earning sufficient income and all other sources of money have been exhausted (Braitstein, Li, Tyndall, Spittal et al., 2003; Mullings et al., 2001; Taylor, 1993). A high proportion of women injectors work in the sex industry and are therefore exposed to greater health risks which may explain why they experience higher levels of mortality than
male injectors (Copeland, 1994). Women's injecting career has been described as 'a career of narrowing options' (Rosenbaum, 1981). Although initially, women's drug use may expand their life, over time, it serves to reduce their options as socially acceptable means of living become more and more restricted through the process of secondary deviance and social labelling (Mullings et al., 2001; Rosenbaum, 1981; Taylor, 1993). MacDonald et al (2003) found that women who had been paid for sex in the last month were more likely than other participants in the survey to report the re-use of someone else's syringe in the past month, indicating that this group of women are at greater risk of contracting blood borne viruses, such as hepatitis C, than other women and other injectors in general. Even when sex work is not considered, women injectors are more likely than male injectors to engage in very risky sexual behaviour\textsuperscript{16} and for there to be different correlates between such sexual behaviour for men and women (Loxley et al., 1998).

**Risks**

Women drug users, and injectors in particular, are exposed to greater risks than their male counterparts. Much of this is because of women's social positioning and the additional social stigma that women experience. It has been found that women are at greater risk of blood borne viruses, such as hepatitis C and HIV through IDU (Baker, Heather, Wodak and Lewin, 2001; Day and Dolan, 2002; Dwyer et al., 1994; MacRae and Aalto, 2000; Miller and Neaigus, 2001; Mullings et al., 2001; Watson, Stevens, Dance and Bammer, 1994). Women find it harder to access sterile injecting equipment than men (Barnard, 1993; Day and Dolan, 2002; Maher, Sargent, Higgs, Crofts et al., 2001), which is related to the additional social stigma they carry. Women drug users fear that by accessing services and

\textsuperscript{16} Very risky sexual behaviour is defined as having had penetrative sex with more than one partner and inconsistent use of barrier protection (Loxley, Bevan and Carruthers, 1998).
identifying as an injector, they may lose custody of their children (Swift, Copeland and Hall, 1996). This goes some way to explaining why they are more likely to share injecting equipment than men (Gossop, Griffiths and Strang, 1994). Several studies have also found that women are more likely to be initiated into drug use, especially IDU, by men (Day and Dolan, 2002; Evans, Forsyth and Gauthier, 2002; Gossop et al., 1994; MacRae and Aalto, 2000; Maher, 1995; Rosenbaum, 1981). There are additional risks of blood borne virus transmission associated with women being initiated into injecting by men, which is exacerbated by the fact that women often have male partners who are older than them, and who have been injecting for a longer period and as such are more likely to have blood borne viruses such as hepatitis C and HIV (Day and Dolan, 2002). Additionally, women are more likely to have a male partner who is also an injector; that is, men are more likely than women to have a partner who is not an injector. This has negative implications for the drug-using career of women and the outcome of treatment (Barnard, 1993; Day and Dolan, 2002; Dwyer et al., 1994; Frischer, Haw, Bloor, Goldberg et al., 1993; Goldberg, 1995; Gossop et al., 1994; MacRae and Aalto, 2000). This has also been implicated in women’s increased risk of violence (Copeland, 1994). Taylor (1993), however, concluded that rather than initiating women into drug use, which implies women have little agency, men were actually more involved in women’s transition from soft to harder drugs and that in fact, women could also act as instigators of drug use in men.

An evaluation of the medically supervised injecting centre in Kings Cross, Sydney, found that women aged 18-25 were the most common users of the service (Mattick, Kimber, Kaldor, MacDonald et al., 2001), indicating that young women value a safe space where they can inject and reduce the risks to which they are exposed. Women are also more likely to experience injection related problems, which can result in an increase in the risk of blood borne virus transmission, as well as damage to veins (Day and Dolan, 2002).
There is a high prevalence of childhood sexual abuse among women injectors, compared with male injectors (Copeland, 1994; Evans et al., 2002; Goldberg, 1995; Maher and Curtis, 1992; Mullings et al., 2001; Vandor et al., 1991), and they are more likely to experience violence and sexual abuse as an adult, than are men (Braitstein et al., 2003; Copeland, 1994; Evans et al., 2002). This abuse has been implicated in the risk of women becoming injectors (Evans et al., 2002; Mullings et al., 2001).

Overall, women are increasingly engaging in risky behaviours and criminal activity (McAllister and Makkai, 2001). Women’s social position means the consequences of engaging in these behaviours are more serious and more likely than for men.

**Drug treatment**

It has been reported that drug treatment services do not generally cater as well for women as they do for men (Copeland, 1994), and that women face more barriers to accessing treatment than do men, and these are greater for women who are mothers or pregnant (Chang, 1994; Copeland and Hall, 1992; Gossop et al., 1994; Kalling Knight, Logan and Simpson, 2001; Lewis et al., 1995; McMahon, Winkel, Suchman and Luthar, 2002; Powis, Gossop, Bury, Payne et al., 2000; Rosenbaum, 1981; Swift and Copeland, 1999; Swift et al., 1996; Taylor, 1993). Treatment models have been produced based upon research with men (and often by men) and so the services are designed to meet the needs of men (Broom, 1994; Chang, 1994; Copeland, 1994; Goldberg, 1995; Hunter and Judd, 1998). Women’s social role as a mother and carer has been implicated as a major reason why existing drug treatments provide inadequate drug treatments for women (Copeland, 1994; Klee, 2002d; Klee, 2002e; Rosenbaum, 1981; Wright, 2002). There are three main reasons cited for this: firstly, the additional levels of stigma women drug users experience; secondly, the risk that
by identifying as a drug-using mother, their children may be removed from their care by authorities; and thirdly there is a lack of childcare provision for women in treatment.¹⁷

It has been reported that women are underrepresented in drug treatment services (Gossop et al., 1994; Klee and Jackson, 1996). However, because the parameters of the female injecting population are not well defined, and because of the underground nature of IDU for women in particular, it is difficult to make such an assessment. Copeland (1994) concluded that there is little Australian evidence that this is the case for women with drug and alcohol problems. That males outnumber females in drug treatment in Australia (Australian Institute of Health and Welfare, 2003) and the UK (Hunter and Judd, 1998) by three to one may mean that women do not access services, but it may also mean that there are simply far fewer female injectors than male, in which case they are not under-represented. In their assessment, Hunter and Judd (1998) concluded that drug treatment services for women were not as inadequate as assumed.

Summary: Gender and injecting drug use

Overall, female drug users face more social isolation, abuse and hardship than men. Women’s drug use is perceived as less socially acceptable than male drug use. Female drug users are usually exposed to greater social, economic and health risks and adversity than their male counterparts. Drug treatment and related services continue to be less accessible to women, largely because they cater for men. Women’s social position is the cause of this disadvantage, particularly because of their primary social role as mother and carer. For mothers in particular, the social stigma and realities of losing their children through

¹⁷ This lack of child care provision during treatment is not however, restricted to drug treatment. It has also been identified as a barrier to women’s health care in general (Broom, 1997).
identifying as a drug user prevent them from accessing the assistance that they need. A more supportive and less punitive approach is necessary to provide these women with the services they require to enable them to meet the requirements of ‘good’ motherhood and ‘good’ womanhood. As they currently stand, health and social authorities can present more of a threat than a source of support to female drug users.

The preceding chapters have outlined the background to the many issues that women with hepatitis C face, and how these are related to childbearing decisions and motherhood. The next two chapters provide a theoretical context for childbearing decisions and motherhood among women with hepatitis C, drawing upon existing theories of deviance and stigma, and the social construction of motherhood.
In this chapter, the theories of deviance and stigma will be used to explain the social positioning of women with hepatitis C, and how hepatitis C affects an individual's social identity and self-perception, that is, how individuals think and feel about themselves as a result of social interaction.

It has been documented that hepatitis C is a highly stigmatised disease in western societies such as Australia, and much of this stigmatisation is related to the IDU that is closely associated with the virus (Anti-Discrimination Board of New South Wales, 2001; Armishaw and Davis, 2002; Gifford et al., 2003; Hopwood and Southgate, 2003). The injection of illicit drugs is widely perceived to be behaviour that is ‘deviant’, which violates social norms, (Boyd, 1999; Goode, 1978; Taylor, 1993) and this is demonstrated through its illicit status, and being labelled a criminal act (Hunt and Derricott, 2001). Several writers have documented how the stigma associated with illicit drug use is considerably more manifest for women than men (Broom, 1994; Copeland, 1994; Goldberg, 1995; Klee, 2002e; Wright, 2002). Certain groups and individuals are at greater risk of having a deviant label applied to them because of their social status (Pfuhl and Henry, 1993; Schur, 1983). This is a key issue that will be explored in more detail throughout the thesis.

A positive hepatitis C diagnosis is a signifier of deviant behaviour because of its strong association with IDU. Those who bear the deviant label as a result of having hepatitis C often experience negative consequences (Gifford et al., 2003; Hopwood and Southgate, 2003). There are several forms of deviance associated with hepatitis C. Firstly, hepatitis C is closely associated with IDU, which in itself is a highly deviant behaviour (Boyd, 1999;
Goode, 1978; Taylor, 1993). Secondly, injectors, or ‘junkies’ as they are commonly perceived, are assumed to possess an array of deviant characteristics, such as being immoral, criminal, lacking self-control and being dirty (Boyd, 1999; Lewis, 2002; Schur, 1983; Taylor, 1993). Thirdly, hepatitis C can represent a form of sickness, which precludes those living with the virus from fulfilling their normal social roles (Parsons, 1951). Individuals who are sick occupy a social role that involves rights and responsibilities different to their normal social roles.

Society reacts to new disease and epidemics with fear (Van Damme and Van Lerberghe, 2000) and attempts to make sense of them through blaming those infected (Nelkin and Gilman, 1991; Van Damme and Van Lerberghe, 2000). By placing blame on ‘others’, society places distance, both symbolically and often in real terms, between those with the disease, and themselves, thus minimising the risk of infection (Quinton, 1991). The placing of blame is rooted in seeking explanations for and finding ways of controlling disease (Nelkin and Gilman, 1991). It is often the socially disadvantaged who suffer most in times of an epidemic, as disease is closely associated with poverty and minority status (Benzeval, Judge and Smaje, 1995; Feinstein, 1993; Kawachi and Kennedy, 1997; Link and Phelan, 1995; Noring, 2000). Consequently, blaming often runs along class and racial lines (Nelkin and Gilman, 1991). As with other diseases such as syphilis and HIV/AIDS, hepatitis C is closely associated with morality and behavioural conduct. Society explains such epidemics in terms of social disease, rather than biological disease by associating the risk and causation of infection with immoral behaviours such as promiscuity and IDU. These epidemics raise societal concerns about social order and values, creating calls for social control through the restriction of the behaviours identified as the cause of the disease.
Deviance theory

Behaviours or attributes that do not conform to the norms of any given society are labelled as deviant. Deviance is defined by Giddens as ‘non-conformity to a given norm or set of norms, which are accepted by a significant number of people in a community or society’ (Giddens, 1993: p116). Pfuhl and Henry (1993) make the distinction between deviance that is ‘achieved,’ through ‘objectionable behaviour’ such as committing a crime (as defined by law), and deviance through ‘ascription’, whereby an individual or group possess ‘objectionable traits,’ such as being blind or of a particular race. People who exhibit deviant behaviour or attributes are socially defined and labelled as ‘deviants,’ and usually experience negative effects from being labelled deviant, because such labels are generally intended to discredit (Schur, 1971).

Specific behaviours are labelled as deviant by the most powerful groups of people in a society (Becker, 1963; Conrad and Schneider, 1980; Link and Phelan, 2001; Pfuhl and Henry, 1993; Schur, 1983). It is these powerful groups of society who define what is right and wrong; they determine morality, and norms are established according to their agenda (Link and Phelan, 2001). Deviance cannot exist unless there are social norms to violate, and every society has norms; thus every society has deviance (Conrad and Schneider, 1980). It may not be that a specific behaviour is exhibited by only a small number of members of society that makes it deviant, but that the members of society who hold most power disapprove of that behaviour because it poses a threat to their social position or ideal social world (Becker, 1963; Conrad and Schneider, 1980). As a form of social control, particular behaviours are labelled deviant and are consequently challenged in some way by other members of society. Behaviour is controlled through rewards for conformity and sanctions against deviance. Both rewards and sanctions may be formal or informal. In the case of
formal sanctions, the legal system punishes those labelled as ‘criminals’ in courts of law. Informal sanctions include rejection by members of society, and reduced life chances to social opportunities through discrimination. Discrimination can take many forms and affect many aspects of an individual’s life (Krieger, 2000).

Many women with hepatitis C are socially marginalised, both economically and socially (Gifford et al., 2003). By labelling and treating them as deviants, and positioning them as the ‘other’ or ‘outsiders’, separate from the rest of society, as described by Becker (1963), more powerful social groups are able to exercise social control over them. According to Becker’s theory of deviance, labelling women with hepatitis C as ‘dirty’ or ‘diseased’, results in them being excluded from some roles in society, which may restrict their employment, or other social opportunities. If women with hepatitis C are not identified and labelled in this way, then these restrictions would not necessarily apply. Identifying women with hepatitis C as current or past IDU discredits them and restricts their access to positions of power and influence.

It is not the behaviour or attributes themselves that are labelled as deviant that is of concern here, but the interpretation of that behaviour or attribute as deviant by society. Behaviour or attributes only become ‘deviant’ when we identify and label them so (Becker, 1963). For example, if we compare the opiates, morphine and heroin, although they are metabolised into the same drug and are the product of the same plant, they are viewed as very different drugs. Heroin is widely perceived to be an ‘evil’ drug, and is the cause of many social ills. This is a view reinforced by its illicit status in western societies. Morphine on the other hand, is viewed in a much more positive light because of its application in western medicine and can be legally prescribed, as was heroin until it was made illegal in the 1960s (Conrad and Schneider, 1980). These two very similar substances are given very
different social meanings because of their associations and are judged based upon prevailing social values.

What is considered to be deviant varies within and across societies. Behaviours or attributes that are labelled as deviant in a society at a particular point in time may not be considered so in other societies or at different times in that same society. ‘Deviance is a matter of interpretive judgment occurring in an established historical, cultural, and situational context’ (Pfuhl and Henry, 1993: p2). In the 1950s, individuals in industrialised societies such as Australia who did not want to marry and have children were perceived to be deviant (Ehrenreich, 1983). Today, there is a far greater acceptance of both delayed marriage and the decision never to marry. To remain intentionally childless is also more socially acceptable today than during the ‘baby-boom’ era of the 1950s (Gillespie, 2001; Hird and Abshoff, 2001). In many developing countries such as those in sub-Saharan Africa, however, marriage (of differing forms) and childbearing (of greater parity than is the norm in western societies) is still expected of the majority of people (Rosen and Conly, 1998). Not conforming to these expectations remains deviant. These examples demonstrate the ways in which deviance is socially constructed and varies within, and across, societies.

Pfuhl and Henry define deviance as: ‘a social construction, created by a process engaged in by humans in their day-to-day interaction with one another…it is people’s behaviour, its interpretation, and evaluation that create and sustain the phenomenon of deviance,’ (1993: p1). The social issues associated with hepatitis C are likely to vary in different cultural settings, largely due to different routes of transmission as well as different social attitudes to illness and the behaviours associated with transmission. There is a large gap in the literature on the social issues surrounding hepatitis C, and especially so for developing
countries such as Egypt, where most hepatitis C infections are through non-sterile medical practice (Crofts, 2001; Frank, Mohamed, Strickland, Lavanchy et al., 2000; Medhat, Shehata, Magder, Mikhail et al., 2002; Rao, Naficy, Darwish, Darwish et al., 2002). Egypt is of particular interest with regards to hepatitis C because it has a very high prevalence of hepatitis C, at 15-20 per cent in the general population (Crofts, 2001; Frank et al., 2000) compared with around 1 per cent in western countries such as Australia, the USA and England (Memon and Memon, 2002) and an overall global prevalence of around 3 per cent (Crofts, 2001; Memon and Memon, 2002; Wasley and Alter, 2000). Existing literature on hepatitis C in Egypt is restricted to biomedical and epidemiological assessments, and as a result there is little understanding of how the virus is socially constructed in Egyptian society. However, because the route of transmission of hepatitis C in Egypt is different to that in countries such as Australia, America and the UK, it may be that the stigma associated with the virus is of a different nature. Wasley and Alter (2000) report there to be at least several different epidemiologies of hepatitis C, which will involve different social meanings and implications (see chapter one for further details). The social meanings given to hepatitis C in these different social environments, along with differences in the routes of transmission, and thus the associations made with the disease, may result in very different social issues for individuals and groups living with the virus. There does not appear to have been any published material investigating this issue, highlighting the need for further research.

Social attitudes towards drug use vary within and across societies (Black, 1991; Blendon and Young, 1998; Copeland and Taylor, 1998) and the attitudes towards women have changed over time and have been well documented, particularly in feminist literature (Badgett, Davidson, Folbre and Lim, 2003; McDonald, 2000; Oakley, 1998; Schur, 1983). The social construction of hepatitis C as an indicator of deviance and as deviant in itself
(where it causes sickness which restricts people’s ability to perform social roles) is variable over time and place and as such is socially constructed.

**Primary and secondary deviance**

According to the theory of primary and secondary deviance, primary deviants are people whose deviant behaviour does not define their social identity (Pfuhl and Henry, 1993). Their deviance is usually concealed and is just one of the many things they do, or one of their many attributes. This is similar to Becker’s (1963) ‘secret deviant’, who exhibits rule-breaking behaviour but who is not perceived to be, or treated as deviant. Secondary deviants are persons whose deviance largely defines their social identity, either because it is not concealable or their deviance has been recognised by other people. This is similar to what Becker described as the ‘pure deviant’, who has broken the rules and is perceived by others to have done so (Becker, 1963). The term secondary is used to indicate that deviance is a process, moving from one stage to another, whereby once the labelling process has begun, primary deviants enter a secondary stage of deviance.

According to labelling theory, once the deviant label is applied, the individual so labelled has reduced access to legitimate ways of living, and as a result, is forced to turn to illegitimate means (further deviant behaviour) to meet their needs (Becker, 1963). The self-concept of the individual who is labelled as deviant is altered because of the way others react to their behaviour. These changes in the self-concept result in continued and escalating deviant behaviour through self-fulfilling prophecy, as legitimate ways of living are restricted (Lemert, 1951).
The deviant career

The process by which individuals transform from primary to secondary deviants has been described as a ‘deviant career’ (Lemert, 1951; Pfuhl and Henry, 1993). Pfuhl and Henry (1993) describe this ‘career’ in four stages (outlined below), representing a simplified version of the eight stages described by Lemert (1951):

Stage 1: Being publicly identified as a rule breaker

Stage 2: Being excluded from participation in non-deviant activities

Stage 3: Coming to define oneself as deviant

Stage 4: Managing one’s own deviant identity

The outcome of this ‘career process’, Pfuhl and Henry (1993) argue, is that the individual is changed categorically and comes to be regarded as ‘essentially deviant’, immoral or ‘defective’. Schur (1971) also highlighted the way in which deviance is a ‘process’, rather than a ‘static entity’ when he described the ‘role engulfment’ that occurs when an individual labelled as deviant internalises the deviant label resulting in a changed self-concept.

Hepatitis C and secondary deviance

Some individuals who inject illicit drugs are able to keep this behaviour secret, and avoid being publicly identified as an injector. Their behaviour is currently defined as deviant, and in fact criminal in contemporary western society. These people represent the ‘secret deviants’ described by Becker (1974). Their behaviour does not shape their social identity through social labelling because other people do not label them as deviants, nor treat them as such. Other injectors are unable to conceal their IDU, for varying reasons, and become ‘secondary’ deviants once others become aware of their behaviour and react to it. The
deviant label is an indicator of that individual’s social identity, and so shapes their lives as others react to that label and everything that it is associated with. Hepatitis C is a signifier of IDU because of the epidemiology of the virus. As such, a hepatitis C diagnosis has the potential to transform someone who is a ‘primary deviant’ to a ‘secondary deviant’ by acting as an indicator of their illicit IDU, and leading to the cumulative process of the ‘deviant career’ as described by Lemert (1951).

The falsely accused

People with an extensive history of IDU are at greater risk of contracting the virus, as the risk of infection increases with duration of IDU (Bell, Batey, Farrell, Crewe et al., 1990; Crofts, Thompson and Kaldor, May 1999; Smyth, Keenan and O'Connor, 1998). However, it only requires one injecting event to become infected with hepatitis C. About 20 per cent of individuals in Australia with hepatitis C did not become infected through IDU (ANCAHRD, 2002). As risk factors such as contaminated blood supplies have been significantly reduced, about 90 per cent of recent Australian infections were estimated to have been through IDU (ANCAHRD, 2002). Although hepatitis C does often accurately indicate current or past IDU, it may also cause the ‘injector’ label to be wrongly applied, which has serious implications for the individual who is incorrectly labelled. It may be that many of the negative experiences of women with hepatitis C who have never injected illicit drugs occurred because they are presumed to be injectors, and in which case this represents the ‘falsely accused’ described by Becker (1963).
**Deviant labels become the master status**

Once someone becomes a ‘secondary deviant’, their deviant label becomes more powerful than the other characteristics that define their social identity. In this way their deviant status obscures all other statuses, and it becomes their ‘master status’ (Pfuhl and Henry, 1993; Schur, 1983). A deviant status is more likely to become a master status than many other statuses (Schur, 1983). Pfuhl and Henry (1993) claim that a deviant master status is perceived to be in conflict with a positive social status, and provide examples of an athlete who is gay and a doctor who is a drug addict. They also highlight the way in which the effects of deviant labelling are not the same for everyone and again demonstrate their point using the example of the drug dependent doctor who is not treated in the same way as the ‘street junkie’ (Pfuhl and Henry, 1993). People of higher SES are more able to defend their non-deviant status and avoid the negative effects of deviant labelling. In regard to women with hepatitis C, women of higher SES may be more able to prevent the deviant master status from being applied to them because it appears to be in conflict with their other statuses. As such, we might expect these women to face fewer barriers to satisfying experiences of childbearing and motherhood. Most hepatitis C infections are through IDU, which is often associated with low levels of education, unemployment and poverty (McAllister and Makkai, 2001). Consequently, we may expect most women with hepatitis C to not be in a strong position to defend their non-deviant identities and as a result will experience severe social marginalisation, as the effects of the various layers of negative labelling are compounding and cumulative.
Hepatitis C and auxiliary traits

Based upon stereotypes, some people are more likely to have a deviant label applied to them (Pfuhl and Henry, 1993). With any deviant label there are associated auxiliary traits. These auxiliary traits form stereotypes, which are characteristics that persons to whom a particular deviant label has been applied are assumed to possess. Pfuhl and Henry (1993) provide the example of the abusive wife who is less likely to be suspected of this form of deviance because of her female characteristics, which are not deemed to be compatible with the emotional and physical violence involved in the abuse of a partner.

According to the labelling theory of deviance described by Lemert (1951), Becker (1974) and Pfuhl and Henry (1993), if a woman with hepatitis C is a mother, and a schoolteacher, her hepatitis C status and the associated ‘injector’ label that accompanies it calls into question her other statuses as mother, teacher and any other social roles she has. In being assumed to be an injector she is suspected of being an abusive, neglectful mother, (Klee, 1998) of poor moral character (Blendon and Young, 1998; Copeland, 1994; Hunt and Derricott, 2001; Lewis et al., 1995) and being ‘dirty’ (Taylor, 1993). Her hepatitis C is an indicator of pollution and immoral behaviour (IDU), as well as being an infectious disease that others may perceive warrants control in order to prevent infection of others (Hopwood and Southgate, 2003). Consequently some members of society may judge her to be unsuitable for motherhood or teaching because of these characteristics she is assumed to have based upon her hepatitis C status. However, the social position she occupies because of her highly regarded occupation, places her in a better position to defend her non-deviant status than another mother who is, for example, unemployed or has an unskilled job. It is not just the hepatitis C status itself that is assessed by other members of
society, but all the attributes that are assumed to accompany it, and in light of the other characteristics they possess, or are assumed to possess. Schoolteachers are not associated with the set of characteristics that are normally associated with being hepatitis C positive. In particular, being a female injector, which is often presumed to be accompanied by low levels of education, poor morality and being involved in criminal behaviour (Taylor, 1993). As a result, the schoolteacher is less likely to be suspected of having any of these characteristics, and thus less likely to be exposed as an injector in the first place.

**Auxiliary traits of women with hepatitis C**

Armishaw and Davis (2002) carried out a somewhat limited study of sexuality among women living with hepatitis C, in which the sample of just six women were all lesbians, who appeared to be comprised of the researcher’s social network. The women in the study described the collection of assumptions made about the person with hepatitis C, largely because the virus is closely associated with IDU, as a ‘package’ of information that accompanies hepatitis C disclosure. The authors argue that, based upon the disclosure of their hepatitis C status, others make assumptions about the behaviour and type of person they are based upon auxiliary traits associated with stereotypes. People with hepatitis C are suspected of having other diseases, such as sexually transmitted infections and of having questionable morals as a result of this process (Armishaw and Davis, 2002).

Pregnancy in western societies almost always involves contact with medical professionals who monitor and oversee the progress of the pregnancy. This contact with the medical profession may involve testing for, or disclosure of, hepatitis C, and subsequent interrogation about current and past IDU, as well as extensive monitoring. This contact with medical professionals is likely to be confronting for most current or past women
injectors (Klee, 2002a), and as such has the potential to prevent these women from accessing obstetrical care (Copeland, 1994; Klee, 2002a; Rutman, Callahan, Lundquist, Jackson et al., 2000). Additionally, it may act as a deterrent to becoming pregnant; women may avoid becoming pregnant because of the fear associated with the questioning and perceived and actual judgement about IDU that they expect to be subject to by medical professionals (Hepburn, 1996; Klee and Jackson, 1996). Additionally, disclosure of hepatitis C in the medical setting may lead to other authorities, such as child protection services, becoming involved in the woman’s life. Again, there is potential for the fear of involvement with such authorities, which have the power to remove their children from their care (Copeland, 1994; Jackson and Klee, 2002; Klee and Jackson, 1996; Rutman et al., 2000), to deter them from having children so that they may avoid such contact. By avoiding health care settings, these women act as secondary deviants, because women in western societies who do not attend for antenatal care are perceived as deviant, in that they are seen to put their child at risk from complications that would be detected and dealt with through such care (Jackson and Klee, 2002).

**Living a double life**

Alonzo and Reynolds (1995) describe the ‘double life’ that people living with HIV/AIDS live by concealing their HIV/AIDS status from people they expect would react negatively to this knowledge. Living such a ‘double life’ involves assuming one set of attributes and behaviours, but to another group of people they exhibit different characteristics and behaviours. This other group of people, who they believe will not apply negative social labels to them in response to such a disclosure, represent those who Goffman (1963) refers to as ‘wise persons’. Female injectors may adopt a similar strategy in order to minimise the effects of being socially labelled as a ‘junkie’. However, their IDU may become visible
through the physical effects of their drug use upon their body, or through social labelling through being caught dealing, using or buying drugs by police and labelled through the formal legal system. A hepatitis C diagnosis represents another means by which IDU can become visible, through medical records and treatment, or the limitations the virus imposes through ill health.

Stigma

The term ‘deviance’ refers to socially unacceptable behaviours or attributes. ‘Stigma’, which is a discrediting mark, or trait, is both an indicator of and the result of deviance. The terms ‘deviance’ and ‘stigma’ appear synonymous because of the notion of norm violation that is central to these concepts. When someone or something is stigmatised, it possesses a trait or characteristics, which among other things may be deviant and often indicate other deviant auxiliary characteristics. Stafford and Scott (1986: p80) describe stigma as ‘relative’; that is ‘what is a stigma in one social unit… may not be so in others’, and as ‘collective’, whereby ‘persons who are devalued by one member of a social unit will also tend to be devalued by other members’. By defining stigma in relation to the violation of norms, both of these features of stigma are recognised and renders this definition very similar to that of the concept of deviance. Deviance is more often applied to violations of behaviour norms, whereas stigma is often used in regard to objectionable marks and physical attributes, as well as to indicate violations of behavioural norms. Stigma is a means of identifying differences between people. The impacts of the stigmatising process are the result of ‘others’ pity, fear, disgust and disapproval of this difference’, whatever that difference may be (Mason, Carlisle, Watkins and Whitehead, 2001).
Stigma is a mark of shame or discredit, or an identifying mark or characteristic. By identifying people in this way, others (usually people in a more powerful social position) are able to avoid them, to distance and protect themselves from the stigmatised for whatever reason, because those persons stigmatised pose some form of threat, whether that be a disease or challenge to their social position or way of life. In his seminal essay, Goffman (1963), defines stigma as an ‘attribute that is deeply discrediting’ and that reduces the bearer ‘from a whole and usual person to a tainted, discounted one.’ Stigmatised identities are social identities to which a discrediting label has been applied, creating what Goffman terms a ‘spoiled identity’.

The large literature that exists on stigma demonstrates the many ways it can be applied. In response to criticisms that the stigma concept is too vaguely defined and individually focused. Link and Phelan (2001: p363) define stigma as ‘the co-occurrence of its components – labelling, stereotyping, separation, status loss, and discrimination’ and that this occurs in a ‘power situation’. There are many different groups of people who experience stigma and the effects of this process are wide ranging (Link and Phelan, 2001). People become stigmatised when they experience status loss and discrimination as a result of social labelling (Link and Phelan, 2001).

According to interactionist theory, every day we are forced to make judgements and categorise people we meet because it is impossible to know everything there is to know about a person’s social identity straight away (Goffman, 1963). We look for signs of their identity, appearance or name, for example, which may give us clues to what kind of person they are and what characteristics they are likely to have. Stigmatised attributes are very powerful, as is the deviant ‘master status’ (Becker, 1963) and are strongly discrediting. All other attributes of a stigmatised individual or group are then called into question based
upon their stigmatised identity (Schur, 1971). Stigmatised attributes impact upon the stigmatised individual’s social identity by creating a filter through which all other characteristics and indicators of an individual’s social identity are seen (Goffman, 1963; Jones, Farina, Hastorf, Markus et al., 1984: p295). The person becomes one of their attributes. The stigmatised individual ‘is’ the thing they are labelled, rather than ‘having’ the attribute (Link and Phelan, 2001). In this case we may expect women with hepatitis C to become a disease, at least symbolically.

There are many consequences of stigmatisation, not all of which affect all stigmatised individuals. In addition to those described by Link and Phelan (2001) these include, but are not exclusive to: low self-esteem, feelings of shame, social isolation and rejection, real and perceived discrimination, financial insecurity, and anxiety (Alonzo and Reynolds, 1995; Goffman, 1963; Klee, 2002d; Link and Phelan, 2001; Quam, 1990; Schur, 1983). The stigmatisation process can contribute to social exclusion, which is ‘what can happen when people or areas suffer from a combination of linked problems such as unemployment, poor skills, low incomes, poor housing, high crime, bad health and family breakdown’; ‘the most important characteristic of which is that these problems are linked and mutually reinforcing, and can combine to create a complex and fast-moving vicious cycle’ (Social Exclusion Unit, 2001). When people perceive themselves to be the victims of discrimination, real or not, this is internalised and impacts upon the self-concept (Link and Phelan, 2001), as discussed above in relation to deviance. As such, stigmatisation has the potential to have far-reaching impacts beyond those resulting from actual discrimination.
Illness as deviance

Parsons (1951) was the first to formally develop a theoretical model of illness as deviance. Parsons argued that sickness is seen as a form of deviance, in which those who are sick are unable to perform their normal social roles, and those who are sick should be returned to a normal healthy state through specified agents of control; these agents are usually a physician, or other medical professionals.

According to Parsons (1951), when the normal social roles that individuals play are affected by their illness, this represents a form of deviance, as they are unable to perform as ‘normal’ and satisfy the requirements of them as members of society. Within the Parsonian paradigm, medical professionals control sickness in the same way that the police control crime. When a person is sick they are excused from and may be removed (to a hospital or other place of care) from their normal daily lives. Once rehabilitated, they are returned to society and the physician, with the co-operation of the patient, takes steps to avoid further illness. Physicians and other medical professionals serve as agents of social control in the case of illness, just as the police and courts deal with criminal deviance to ensure the smooth functioning of society.

It is useful in this analysis of deviance to establish the distinction between the terms ‘disease’, ‘illness’ and ‘sickness’. The term ‘disease’ refers to a biological change within the body. ‘Illness’ refers to the individual’s experience and interpretation of disease. ‘Sickness’ refers to the social positioning of an individual experiencing illness (Christopoulos, 2001; Epstein, 1995). Kleinman et al (1978) highlight, however, that it is possible to experience illness without disease, as it is not uncommon for people to report health complaints, yet medical practitioners can find no biological explanation for their complaints.
Parson’s sick role (1951) legitimises deviance that has been socially defined as illness, and in doing so, removes the individual responsibility for the deviance away from the deviant. The medical professional is the person mainly and ultimately responsible for legitimising the sick role, although family, friends and other members of a community may be involved in negotiations (Twaddle, 1981).

People may also be considered deviant when they have a health related permanent disability or deformity. In the case of a disability, their inability to perform certain tasks marks them out as different from other members of society, thus making them deviant. People with deformities are labelled as deviant for different reasons, not necessarily relating to their ability to perform particular roles or tasks.

There are four main components of the sick role, as Parsons (1951) defined it. These can be divided into rights and duties, as indicated below.

The sick person:

Right 1: Is exempted from normal social obligations and responsibilities

Right 2: Is not blamed for their condition. The responsibility for the management of the subsequent illness rests with medical professionals.

Duty 1: Must consider their state of illness as undesirable, to wish to get better and return to their normal social role as soon as possible.

Duty 2: Must seek appropriate help, usually from medical professionals and cooperate with their recommendations.
Medicalisation of deviance

The term medicalisation is used to describe the process whereby ‘non-medical problems are redefined as medical and are identified and dealt with by the medical profession; physical conditions do not, by their nature, constitute illness, rather, they require identification and classification, which entail subjective and value-laden considerations’ (Roach Anleu, 1999: p99). Just as the notion of deviance is socially constructed, the phenomena we describe as illness are too. What behaviour or phenomenon is labelled as ‘illness’ rather than another form of deviance, such as crime, is socially determined. Medicalisation represents a form of social labelling, in which particular phenomena (symptoms) are identified and labelled as disease, which are then translated into illness and sickness. People too can become medicalised as their social identity becomes defined by the clinical markers used to assess their condition (Hopwood and Southgate, 2003).

Medicalisation can be thought of as medicine achieving ‘the authority to define problems as ‘sickness rather than ‘badness’, (Conrad and Schneider, 1980: p8-9), or defining something natural, such as childbirth or menarche, as a medical problem (Broom and Woodward, 1996). For example, Crawford and Heather (1987) discuss the changing social attitudes towards alcoholism and describe the way that alcoholism is now more widely accepted as a disease by the general public. More recently, addiction has been explained based upon neuroscience (Hall, Carter and Morley, 2003; Kleiman, 2003; Uhl, 2003). This has a number of implications, as within the neuroscience explanation of addiction, people with a drug addiction do not have any control over their drug-taking. The social labelling of addiction as a medical problem means that individuals who exhibit this behaviour are placed in Parsons’ (1951) sick role, rather than in a criminal role. The sick role involves different rights and responsibilities than would be the case if they were treated as criminals. Kleiman
(2003) highlights that it is less justifiable to punish someone for behaviour over which they have no control. By medicalising addiction in this way, the notion of blame is removed from the drug dependent individual and so the way in which society deals with this behaviour is focussed upon medical treatment, rather than punishment.

Based upon the notion of addiction being socially labelled as a disease, rather than a moral problem, we might expect social attitudes to dependent injectors be more lenient and less punitive. However, approaches to the ‘drug problem’ such as the highly punitive ‘War on Drugs’ policy adopted by the USA (Black, 1991; Blendon and Young, 1998) indicate that there remains a significant degree of blame placed upon illicit drug users for their dependence associated behaviours. Problematic drug use is concentrated among people of low SES. In particular, drug use is associated with people of minority ethnic groups, low income; and unemployment, who are blamed for this social disease (Beckett, 1995; Lynch, Kaplan and Salonen, 1997; Nelkin and Gilman, 1991).

Methadone maintenance treatment (MMT), which is widely used to treat heroin addiction, is essentially a form of social control (Southgate, 2003). Lilly et al (2000) highlight that MMT is more than a clinical encounter in which an appropriate dose is agreed upon, and is in fact ‘a social interactional process’, with the ‘sociality of treatment’ being ‘embedded within the negotiation and building of social roles and relationships more generally’ (p163). Conrad and Schneider (1980: p29) claim that ‘medicine functions…to secure adherence to social norms − specifically, by using medical means to minimize, eliminate, or normalise deviant behaviour,’ and MMT provides a clear example of such a form of social control.

MMT, along with needle and syringe programs, reduces drug-related harm to drug users and the wider community (The Royal Australasian College of Physicians, 2004). Methadone
maintenance is, however, perceived to have social costs (Brandt, 1991); in terms of the financial costs of providing it and in terms of appearing to support people who break the law by using heroin.\(^{18}\) Demand for MMT and other drug treatments in Australia currently outstrips supply, even though the number of treatment places for MMT has increased significantly (The Royal Australasian College of Physicians, 2004). In rhetoric, the Australian Government advocates medical treatment for drug dependence, including pharmacotherapies such as MMT, as part of a harm minimisation strategy. This is based upon weighty evidence that such treatments are relatively low cost, effective and safe (The Royal Australasian College of Physicians, 2004). However, government funding of such programs is wholly inadequate and is influenced by ‘populist policies and programs promoting ineffective methods over proven ones’ (The Royal Australasian College of Physicians, 2004: p8). These populist policies are based on a ‘drug-free’, abstinence based approach which is largely punitive and far less effective than the harm minimisation approach (The Royal Australasian College of Physicians, 2004).

Wider social perceptions and attitudes to such deviance change, albeit not necessarily immediately, nor uniformly. The medical model that is dominant in western society defines deviant behaviours and conditions differently to legal and religious doctrines. Kleinman et al (1978) highlight the way in which medical professionals often deal with illness

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\(^{18}\) An ABC documentary (Bowden and Robinson, 2004) recently presented the controversial issue of takeaway methadone from a very negative perspective. Takeaway methadone doses are taken away from the dispensing clinic or pharmacy so that people on the program do not have to attend every day. In the documentary, there were tokenistic positive comments from a leading methadone prescriber and a single mother who was on the takeaway methadone program. However, most of the broadcast featured grieving parents of people who had lost lives though the use of (and non-consensual administration of) diverted takeaway methadone. The documentary neglected the overall aims of the methadone program and the great benefits it provides not only to people on the programme, but also to wider society. It also neglected to consider that had diverted methadone not been available, any number of legally prescribed diverted drugs might have been used instead and possibly had the same fatal consequences. Rather, the takeaway methadone programme was presented as supporting the abuse of methadone, presumably because it is used to treat heroin dependence, which makes it more deviant, rather than facilitating a more stable, functioning life. This television broadcast reflects a wider conservative, non-evidence based social perspective of drug dependence treatment.
inadequately. They argue that medical professionals fail to consider the individual’s experiences of disease and other phenomena that are defined as illness and the social meanings of the illness that they experience. Kleinman et al (1978) state that doctors must look beyond disease and consider the ways in which illness is socially constructed, and how this varies across time and space in order to ‘heal’ the individual and not simply ‘cure’ the disease.

The right to the sick role

The severity and duration of illness may play a part in determining whether or not the sick role is awarded. However, there may also be other reasons why the sick role is not awarded, such as the behaviour of the individual, especially if that behaviour can be identified as the cause of the illness. Quam (1990) discusses the way in which people living with AIDS may be denied the sick role, as Parsons (1951) described it, because they are held to blame for their condition to some extent, because the virus is associated with homosexuality, which is considered deviant. As a result, when people living with AIDS are denied the sick role, they are instead treated as criminals. Conversely, people living with HIV/AIDS may have the sick role imposed upon them because of a lack of consensus about how people living with the virus should behave, that is, what social roles they should perform, because Parsons’ (1951) sick role does not accommodate the chronic and fluctuating nature of the illness caused by HIV/AIDS. While chronic conditions may attract less legitimation of the sick role, Honig-Parnass (1981) found that people living with chronic conditions tend to receive care and have their role expectations defined by significant lay people, such as partners or parents, rather than by professionals. Thus the role of both the physician and patient in the management of chronic conditions is at best a grey area, and one that certainly does not fit Parsons’ (1951) conception of the sick role.
The sick role and stigmatised chronic diseases

There are a number of parallels in the criticisms Quam (1990) makes of the sick role in relation to AIDS, when compared to people living with hepatitis C. Firstly, as for HIV/AIDS, there are notions of blame associated with hepatitis C because of the deviant behaviour (IDU) with which it is associated. As a result, people living with hepatitis C may be treated as criminals, rather than someone who is sick, which has significantly different social implications. Secondly, hepatitis C, like HIV/AIDS is a chronic disease, and produces fluctuating symptoms. Within the sick role that Parsons described, persons occupying the sick role are expected to return to good health and subsequently assume their normal social roles. While people living with a chronic condition such as HIV/AIDS or hepatitis C may be able to return to most of their normal social roles after a period during which they experienced debilitating symptoms, they can never fully return to their original social roles in the same way that they would if their condition was acute and more like the way Parsons envisioned sickness to be. Thirdly, like HIV/AIDS, treatments for hepatitis C are limited, yet despite this people living with these viruses are still expected to be under the supervision and treatment of medical professionals, which implies a form of social control. The medical treatments currently available for hepatitis C can produce severe and debilitating side effects (Smith, 2003), as they can for HIV/AIDS (Quam, 1990). Additionally, current treatments for chronic hepatitis C are limited in that they are not suitable for all people living with hepatitis C or all genotypes of the hepatitis C virus, as well as having adverse side effects (Trepo, 2000).

Summary: Deviance, stigma and women with hepatitis C

IDU among women is viewed as more deviant than among men for a variety of reasons based upon gendered social norms. One of the primary reasons for this is that such
behaviour is not compatible with women’s role or their potential role as a mother
(Copeland, 1994; Klee, 2002c). ‘Illicit drug use by women is less socially acceptable and
more stigmatising than men’s, with women labelled as deviants for their drug use but
additionally for breaching society’s definitions of feminine behaviour’ (Wright, 2002: p19).
Definitions of feminine behaviour vary among different societies, but generally centre on
women’s roles as mother and carer, (Lawler, 1996) and as upholders of morality (Albury,
1999). Perceived deviance among many women living with hepatitis C may affect the
childbearing and motherhood experiences of women living with hepatitis C. The nature of
the social labelling that women living with hepatitis C experience will be investigated in
subsequent chapters through the analysis of semi-structured interviews with a range of
women living with hepatitis C.

Women with hepatitis C are subject to multiple stigmas, which are each related back to
their assumed deviant status. Firstly, hepatitis C is closely associated with IDU, a behaviour
that is particularly scorned upon for women (Barnard, 1993; Broom, 1994; Copeland and
Hall, 1992; Dwyer et al., 1994; Ettorre, 1994; Goldberg, 1995; Hunter and Judd, 1998;
Mulia, 2000; Rosenbaum, 1981; Taylor, 1993; Vandor et al., 1991; Wright, 2002). That
hepatitis C is infectious and potentially fatal results in further stigmatisation (Hopwood and
Southgate, 2003). It is suggested in this thesis that both of these potential stigmas are
particularly damaging in relation to motherhood. If women with hepatitis C already have
children, their ability to be a ‘good mother’, based upon her stigmatised identities as an
assumed injector and carrier of an infectious potentially deadly virus, along with their
associated auxiliary traits, is questioned. Should these women be found to be ‘bad mothers’
for whatever reason, creates further stigmatisation. This process of cumulative deviant
identities supports the notion of ‘secondary deviance’ based upon labelling theory. Such a
‘spoiled identity’, as described by Goffman (1963) can lead to personal and social
condemnation and social isolation (Murphy and Rosenbaum, 1995). If she is not yet a mother, a woman’s appropriateness to become a mother is assessed based upon these ‘spoiled identities.’ Barriers may be erected to try to prevent her from becoming a mother in light of her being suspected to be unsuitable for the role. A childless woman represents yet another potential stigmatised identity. Childlessness remains considered to be a generally negative characteristic of a woman and may be cited as an indicator of her suspect moral character and socially undervalued characteristics (Albury, 1999; Hird and Abshoff, 2001; Romito, 1998).

The concept of stigma is central to the study of childbearing and motherhood among women living with hepatitis C. Stigma is pivotal to their social identity and social realities. The manifestations of ‘spoiled identities’ are seen in terms of the discrimination and social rejection they experience. Women with hepatitis C are subject to stigmatisation based on a number of labels and stereotypes that may be applied to them. These labels include being ‘dirty’, ‘diseased’, ‘smackheads’, ‘junkies’ and ‘immoral’. Women who have never injected illicit drugs are often suspected of being current or past injectors based on their hepatitis C status. Only when an alternative source of infection is established and is accepted as the truth by others are they able to shed the stigmatised label of being an injector, and this process may have to be repeated, for example each time they see a new doctor.

Once we add to the equation the question of motherhood, the stigmatised identity becomes even more complex. Women are often criticised for ‘bad’ mothering, which carries a high degree of stigma. The moral character and female identity of women is stained by hepatitis C and her ability to be a ‘good’ mother is scrutinized based upon her ‘master status’ as a deviant. This chapter has demonstrated how the application of a deviant ‘master status’ overrides the other statuses of an individual, and how the other aspects of a
person’s life are then ‘filtered’ through this deviant layer and subsequently challenged. When we apply this to women with hepatitis C, it may be the case that once identified as being hepatitis C positive, their abilities as mothers are then questioned, based upon their ‘infectious state’ and the assumptions that such people must be of poor character. This thesis aims to examine the ways women with hepatitis C are stigmatised and how they experience and respond to it. This thesis will examine how they manage information, that is, to whom and when do they disclose their hepatitis C status, and what are the implications of this. It will examine women’s perceptions of this stigmatisation and how this affects their lives. The ways in which stigma influences their childbearing decisions and how it affects their role as mother are investigated in detail.
Chapter 5: The Social Construction of Motherhood and
Women with Hepatitis C

The social construction of motherhood is inextricably linked with the way women are perceived and positioned in society. This section will explore the current ideology of motherhood and the implications of this for women with hepatitis C. It is suggested that the ideology of motherhood acts to further marginalise women with hepatitis C, by restricting their ability to develop a socially acceptable role and social identity.

Despite significant social changes over recent decades in which fertility rates have declined considerably, most Australian women continue to become mothers at some point in their lives. While Australian women are having children later in life than in previous years (Australian Bureau of Statistics, 2002b), only a very small proportion remain childless. In 2001, 13 per cent of 40-44 year old women were childless (Australian Bureau of Statistics, 2002c). The proportion of women who remain childless is, however, steadily increasing (Australian Bureau of Statistics, 2002c). Additionally, more women are currently in paid employment than ever before (Australian Bureau of Statistics, 2002c). Despite these changes, motherhood remains central to the feminine identity within contemporary Australian and other industrialised societies (Albury, 1999; Blyth and Moore, 2001; Crouch and Manderson, 1993; Hird and Abshoff, 2001; Ireland, 1993; Lawler, 1996; Morell, 2000; Rich, 1984; Williams, 2004; Woollett, 1991).

There have also been significant changes in the forms of family found in Australia, with a move away from the traditional nuclear family with other types appearing to be increasingly socially acceptable (McDonald, 2003). The social situations in which birth and childrearing are taking place are expanding. Since the 1980s there are many more families comprised of
single mothers, older mothers, lesbian mothers (Crouch and Manderson, 1993) and gay men in western societies such as Australia. However, Schur (1983) indicates that it is often people in higher social positions who are able to challenge dominant ideals and not be subjected to the stigma and discrimination that they would otherwise experience. Methods of conception have also changed due to recent technologies that allow individuals and couples to use sperm donors, in-vitro fertilisation (IVF) treatments, and surrogate mothers. All of these developments have led to a reassessment of what it means to be a mother, and indeed a parent.

The social control of childbearing and motherhood

Although we are now seeing different forms of family and parenting (and means of conception), there remain a number of constraints that limit the social situations in which childbirth and parenthood are deemed acceptable or appropriate. Social and legal controls remain in place to attempt to limit childbearing and motherhood to certain ideal conditions (Phoenix and Woollett, 1991). Although most women are expected to, and do become mothers, their age, marital and financial status, health, educational attainment and moral standing, and even race or religion are assessed in terms of their acceptability to mother. If women wish to have children in what are considered to be less than ideal conditions, attempts of varying nature and severity are made by different sectors of society to dissuade and/or prevent them from doing so. These actions serve to marginalise those labelled inappropriate or unfit mothers.
The social construction of motherhood

In most societies, women are charged with the duty of caring for children. Throughout modern history, this has been justified based upon women’s supposed biological and psychological characteristics that make them more amenable to the task (and less suitable for work outside the home). This has largely determined the gendered division of labour in industrialised societies. Nature is often cited in explaining differences between the sexes and women’s instinctual desire for children and their supposed natural propensity and ability to care for children. However, both feminists and cross-cultural analysts have revealed how mothering is socially constructed and not biologically determined (Nakano Glenn, Chang and Rennie Forcey, 1994; Palmer, 1998).

Parenthood

The terms, ‘mother’ and ‘father’, within industrialised society, have very different connotations, although both describe the role of being a parent. There are clear distinctions made about what the parenting role entails, based upon gender. To mother not only means to have given birth to a child, but also to be the primary carer of that child over an extended period of time, through to adulthood. To father, however, can be limited to the biological role that a man played in conception (Chodorow, 1978). Where the term ‘father’ is used to describe male parenting, the role of ‘father’ is often limited to specific aspects of childcare, such as playtime or discipline. Seldom is the term ‘father’ used to refer to the everyday care of a child, that is, meeting it’s every need for food, warmth, cleanliness, and affection. This is because these are tasks predominantly allocated to the mother. However, significant social changes in recent decades have led to the greater use of the term ‘parenthood’ rather than ‘motherhood’ or ‘fatherhood’, which demonstrates increasing recognition that many aspects of childcare can be performed by either male or female.
Indeed, there is evidence that men are now expected to play a greater role in aspects of childcare traditionally performed by women (Commonwealth Department of Family and Community Services, 1999; Commonwealth of Australia, 2002; Fletcher, 2003).

Recent studies into the fatherhood role in contemporary western societies have shown that while there have been some changes in the parenting roles of men, ‘the role of the father remains stereotypically gendered’ (Commonwealth Department of Family and Community Services, 1999) and largely limited to play, sport and being involved with their sons. Meanwhile women are more responsible for the day-to-day care of children, their health problems and involvement with daughters (Howard, 2003). Although there has been significant change in attitudes and policy regarding fatherhood, the situation that Wearing described has persisted to some degree: ‘through the ideology of motherhood, men are relieved of the obligation to take care of children and are in a position to perpetuate this ideology and the aspects of it which also legitimate their relative freedom from other domestic responsibilities’ (Wearing, 1984: p23).

**Ideologies of motherhood**

The concept of motherhood is discussed here in terms of the ‘ideology of motherhood’. An ideology represents the viewpoint of a dominant group. It is ‘the conceptual system by which a group makes sense of, and thinks about the world’ (Nakano Glenn et al., 1994: p9). An ideology is a collective rather than an individual phenomenon. The norms and ideals an ideology encapsulates need not be shared by everyone in the group, or even the majority of the group, but are controlled by the dominant groups or members of society to serve their own needs.
Despite huge social changes in the late 20th century, many of the more traditional tenets of the ideology of motherhood remain at the heart of contemporary social organization. Although there have been enormous changes in the social roles of women and attitudes towards sexual equality, contemporary western society remains largely dominated, and organised, by men. Present day ideologies of motherhood act to serve the needs of men through male dominated gender relations, although there exists a great deal of variation within western societies, according to age, social class, education and race (Albury, 1999; Chodorow, 1978; Everingham, 1994; Gordon, 1990; Gross, 1998; Lawler, 1996). There are different expectations made of university educated women for example, when compared to women with low levels of education. Rather than their social role being restricted to mothering, many educated women are expected to put their work ahead of family plans. The social expectations of women with little education and earning power, however, tend to revolve around motherhood and other feminine tasks, such as caring and domestic duties. Women of higher SES tend to have more legitimate social roles open to them; social expectations of women vary according to their SES.

The ideology of motherhood in western societies portrays mothers as self-sacrificing, caring, and virtuous, with character traits of nurturance, and lack of competitiveness (Boyd, 1999; Klee, 2002e; Lawler, 1996: p153). All of these characteristics are conducive to good mothering based upon the tenets of motherhood identified by Wearing (1984: p33), which are outlined and discussed below.
Wearing’s tenets of motherhood:

1. Motherhood is an essential part of womanhood;
2. Motherhood is hard but rewarding work;
3. A 'good' mother puts her children first;
4. Young children need their mothers in constant attendance.

**Motherhood is an essential part of womanhood**

Womanhood and motherhood go hand in hand; motherhood being central to the notion of womanhood and femininity. Women who reject motherhood are perceived as infantile and un-feminine and because a woman’s identity is based on her capacity to give birth, women who remain childless are viewed as deviants against ‘nature’ (Hird and Abshoff, 2001: p360). To be childless can challenge one’s identity as a woman, and on the whole, is considered to varying degrees, dependent on SES and the socio-cultural environment, to be deviant. Intentionally childless women are often perceived to want to be like men, that is, unfeminine, since they wish to focus their energies on their career and self-fulfilment (Hird and Abshoff, 2001), which are interests and desires that are deemed male. Motherhood need only represent one aspect of a woman’s life and identity, which may also be temporary, as Oakley (1979b) describes. Lawler (1996), however, maintains that motherhood is often interpreted as a woman’s whole and permanent identity. For some women, this may be the case, as Hill (1994) found for American women of low SES. Rather than being a whole identity, contemporary motherhood remains perceived as the most important of female social roles (Crouch and Manderson, 1993; Gillespie, 2001).
Motherhood is hard but rewarding work

The role of mother in industrialised societies has been romanticised as a labour of love and as a result has become invisible and unpaid. Maternal work is assumed to be a ‘natural’ component of a woman’s feminine identity and subsequently it is not recognised, or paid as work (Lawler, 1996). There is, however, scant evidence for this biological instinct (Boyd, 1999).

Motherhood represents ‘women’s strengths, power and potency’ (Gillespie, 2001: p141), and provides status, but not power (Nakano Glenn, 1994). Crouch and Manderson (1993) describe motherhood as both an identity and an occupation. By becoming the caring and giving, selfless woman that the ideology of ‘good motherhood’ demands, women are disempowered and stripped of their other identities and social roles, and can be perceived to lose their sense of self and liberty (Crouch and Manderson, 1993). Once a woman bears children, she often becomes dependent on her partner, the state or other sources of support because her ability to work, to influence social institutions, achieve independence and self-fulfilment in public life become limited (Everingham, 1994). As women’s social roles become more diverse over time, perceptions of motherhood are beginning to change.

If women do not conform to the contemporary ideology of motherhood and instead set out to achieve goals outside of those prescribed for women, they are labelled deviant and subject to social sanction as a result. This is not the case for all women and there are different expectations made of women based upon race, religion, class, educational attainment and age. Women have achieved increasing levels of autonomy over time and it is now more possible, and expected among most women, to be a mother and to pursue a career as well (Gross, 1998; McDonald, 2003).
A good mother puts her children first and young children need their mothers in constant attendance

Hays (1996) identified a number of assumptions on which the contemporary notion of ‘intensive mothering’ is based: mothers are the ideal carers of children; expert-guided, emotionally absorbing, and labour-intensive child rearing is best; children are sacred and their wellbeing valued above all else. Each of these assumptions will now be discussed. Throughout the late 20th century the notion of ‘intensive motherhood’ has been widely adopted as the ideal model of motherhood.

These assumptions reinforce the perspective that women’s primary role is of child carer and that self-sacrifice is required in order to do this properly. Within the ideology of ‘intensive mothering’, mothers are expected to always be there for their children, to offer consistent care and for their children to be of importance, above all else. This ideology of motherhood is governed by two quite separate discourses: the ‘natural’ and the ‘expert’ (Lewis, 2002), both of which are governed by men and serve to maintain women’s subordinate position. Mothers who do not conform to these ideals are often deemed unfit or bad mothers. Lawler (1996: p154) claims that ‘the ideology of the perfect mother creates a standard that no human being could attain’ and results in tremendous feelings of guilt for many mothers. ‘Intensive mothering’ denies women of their own needs, aspirations and desires (Gross, 1998), which must be sacrificed in order to satisfy the needs of her children and male partner. Women are held entirely responsible for the outcome of the pregnancy and their mothering (Boyd and Faith, 1999; Boyd, 1999; Phoenix, Woollett and Lloyd, 1991), and this restricts their opportunities to achieve their other aspirations (Schur, 1983: p81). By making women solely responsible for the adults that their children eventually become enables society to place a great deal of blame upon women for many social ills, with little regard for the social circumstances that lead to her ‘failings’ (Waldby,
1988). Boyd (1999) claims that the ‘War on Drugs’ has become a ‘War on Women’ because it is women who are held accountable for much of the societal damage associated with drug use and it is often women who are punished through both the legal system and other social sanctions. By charging women with society’s problems disguises the patriarchal systems that dominate and create such social problems. As it is currently socially prescribed, motherhood has become unattractive to many women, particularly those for whom there are alternative socially acceptable roles.

**Summary: the ideology of motherhood**

Women are paradoxically ‘idealised and blamed’ for not meeting societies expectations (Lewis, 2002: p32). When mothers are seen to fall short of the ideal standard they are labelled as deviant and treated as such. Murphy and Rosenbaum (1999: p134) detail how American women described personal and social condemnation and social isolation as the consequences of being labelled an unfit mother. Such labelling can further hinder efforts to be a good mother and conceal the supports mothers need and prevent them from accessing assistance (Lewis, 2002).

Society perceives women quite paradoxically, that is as ‘pure and selfless mothers’, with little autonomy; yet also as ‘sexy bitches or aggressive careerists’ (Oakley, 1993: p89). In terms of childbearing, women are subject to public sanction if they do not desire children, or if they have them under the wrong circumstances. Even if they have children within the prescribed circumstances, women’s methods of mothering always remain open to questioning and criticism.
While there is some degree of acceptance of men abandoning their parenting responsibilities (financial and otherwise) at various stages of fatherhood, for a woman to do so would create quite a different social response. When a man is a ‘good father’ he is often openly appraised for it, but women are expected to be a ‘good mother’ and only come to attention when they do not live up to expectations of ‘good motherhood’. Schur (1983: p88) highlights that although mothers may be deemed ‘unfit’, it is unusual for men to be described as an ‘unfit father’. In any case, the stigma and consequences of such a label being applied to men are less severe than for women. Schur (1983) explains that this is because men are not expected to be responsible for childrearing to the same degree as women. However, there has been an increased academic and political interest in the fatherhood role in recent years. In general the absence of a father is perceived to have negative implications for children and wider society (Commonwealth Department of Family and Community Services, 1999). In response, western governments, including the UK, USA and Australia (Baskerville, 2002; Collier, 2001; Commonwealth of Australia, 2002; Fletcher, 2003; Howard, 2003) have introduced policy changes and funding to encourage greater paternal involvement in the raising of children. Unlike men, almost every aspect of a woman’s life can be brought into an assessment of her ‘fitness’ to be a mother (Phoenix and Woollett, 1991; Schur, 1983). This might include her lifestyle, friends, drug or alcohol use (Lewis, 2002), and appearance.

Superwoman

Professional ideas of motherhood that are imposed upon women are often quite different to the actual experiences of mothers (Oakley, 1993). The so-called experts portray ‘good’ mothers as normal, yet few women live up to this ideal (Phoenix and Woollett, 1991; Swigart, 1991). There has been a move away from the ‘intensive motherhood’ ideology, to
one in which women are often expected to cater to the every whim of their children and male partner at the same time as attempting to establish an identity and achieve success outside the home. However, many of the values of ‘intensive mothering’ have been maintained, and women are now expected to provide a modified version of ‘intensive mothering’ as well as managing a career. These pressures to perform in all aspects of life can be the source of great stress and induce feelings of inadequacy, failure and guilt (Gross, 1998; Oakley, 1979b; Swigart, 1991).

**Desire for children and childlessness**

The desire for children, or to remain childless, is inextricably linked with the notion of motherhood being part of womanhood. Being a mother is central to what it means to be a woman. Desire for children presents a number of complex issues. One may argue that women are so conditioned to want children, that when asked why they want children, many may not be able to give a clear answer. In fact, ‘maternity is such a taken for granted aspect of life that it rarely rates much public attention’ (Reiger, 2000). Oakley (1979a) found that many women had never asked themselves the question of why they wanted a child, but other women had considered this question extensively. Women have often described their wanting a child in terms of natural instinct, or a need to mother; many never questioned their desire because it is so intrinsic to their identity as a woman and may never have considered an alternative role or identity. Further complexity is discovered when enquiring about the planning of pregnancy. Women’s ideas of what it means for a pregnancy to be ‘planned’ or ‘unplanned’ can vary enormously, and for many it is meaningless (Barrett and Wellings, 2002; Moos, Petersen, Meadows, Melvin et al., 1997).
Intentional childlessness

Intentionally childless couples (but especially women) can be perceived as ‘selfish, maladjusted, incomplete, unloving, irresponsible, unnatural, immature, materialistic, individualistic, too career-oriented, lonely, unhappy, child-haters, and even psychologically unstable’ (Hird and Abshoff, 2001: p354). If women do not become mothers, they are not known simply as women, but as ‘not-mothers’ and their childlessness is what defines them (Lawler, 1996: p155). Childfree desire is often interpreted negatively, rather than conveyed positively, as what childless women want (Lievore, 2001). Women often have desires outside of, or that exclude, motherhood. For some, the obstacles to motherhood may be too great to overcome in relation to their other desires. Women who choose not to have children are perceived as inadequate based upon motherhood being an idealised standard (Morrell, 1993).

Women with higher levels of education and higher incomes are over-represented among those who choose not to have children (Gillespie, 2001). This may be because it is these women who have more choice about whether or not to have children. They may have other socially acceptable roles and identities open to them. It may also be the case that by choosing not to have children, this has afforded them other opportunities and allowed them to avoid the dependency that other women fall into through having children.

The social construction of motherhood and women with hepatitis C

Although women now have more life choices than in the past, whether or not they are a mother remains a primary determinant of their social identity. The effect that living with hepatitis C has upon women’s lives, as opposed to the impact it has upon men’s lives, is
differentiated by women’s identity as a mother, potential mother, or non-mother. The
literature indicates that for a number of reasons, women with hepatitis C who have
children may meet with social disapproval. It is unlikely that men with hepatitis C
experience similar negative effects of being labelled an ‘unfit father’ to the same degree,
because it is women, rather than men, who are expected to provide intensive care of
children, and for this to be women’s primary role.

As demonstrated in the previous chapter on deviance and stigma, women deviants are
often judged and reprimanded more harshly than their male counterparts. For women with
hepatitis C this is of particular relevance. In being a mother, or potential mother, certain
types of behaviour are considered highly inappropriate. Mothers are expected to be
virtuous, caring, nurturing and self-sacrificing (Albury, 1999; Crouch and Manderson, 1993;
Klee, Jackson and Lewis, 2002; Lawler, 1996; Lewis, 2002; Swigart, 1991; Wearing, 1984)
and the same is generally expected from potential mothers (i.e., women). The stereotypical
woman with hepatitis C may be seen to possess few or none of these traits. Her moral
character is presumed to be flawed, based upon her assumed drug use, which is used as an
indicator that she is self-indulgent, reckless and dangerous. Women with hepatitis C may be
perceived to be ‘polluted’, both physically in terms of the virus in her blood, and socially
through the deviant circles she has moved in as a drug user (Taylor, 1993). The ideal
characteristics that mothers are required to have may be presumed to be absent among
women with hepatitis C and so women with hepatitis C are likely to be deemed by many to
be inappropriate for motherhood. Women drug users, (and women with hepatitis C by
association), are often believed to be untrustworthy, immature, promiscuous, irresponsible
and inadequate (Taylor, 1993), all of which are characteristics considered unsuitable for
motherhood (Lewis, 2002). Because of the strong link between hepatitis C and drug use,
women with hepatitis C are likely to be assumed to have the same characteristics as
stereotypical ‘junkies’ and thus to be unfit mothers. Being labelled inappropriate for motherhood is tantamount to being a ‘bad’ woman who is consequently excluded from normal social circles. Social labelling that induces such exclusion may lead to further deviance, a process known as ‘secondary deviance’ (Lemert, 1951; Pfuhl and Henry, 1993).

Although many other women do not meet all the criteria set by society required to be a good mother, the assumed and real characteristics of women with hepatitis C are particularly unsuitable for motherhood. This is based upon the stigma and deviance associated with both the virus and their assumed IDU. The way that charities use emotive images of drug-using mothers and present their children as innocent victims in order to raise funds demonstrates the extent of the contempt felt towards drug-using women. The Barnardos Australia May 2003 appeal provides such an example (Figure 1). The television and billboard components of this campaign featured a dishevelled little girl neglected by her drug-using mother. In publicising the more extreme cases of child abuse and neglect associated with substance use, they demonise mothers who use drugs. These women are in need of assistance, rather than the judgement and social sanctions that such images provoke. The social reaction to appeals like this further disempowers women drug-users and compound the disadvantage experienced by their children. Such appeals point the finger of blame solely on the mother, and disguise the social and economic systems that have actually caused such a situation to occur.
May Appeal 2003
As one of our major bi-annual appeals, the May Appeal 2003 has a major goal this year - to raise over $500,000.00 which is urgently need to ensure the continuation of our welfare services and programs.

The theme of the May Appeal 2003 is ‘Katie has a drug problem - Her mum’ - every day children are neglected and abused by drug dependant parents. By donating to Barnardos you can give children like Katie the help they’ve been missing.


The NSW Commission for Children and Young People (2004) highlighted that ‘half the families of children who died as a result of inadequate supervision lived in families that had other difficulties including financial, relationship or drug and alcohol problems’. This indicates that among these families there is a real need for support. At present it seems that the role of concerned authorities is more punitive than supportive, and as such, potential sources of support are in fact perceived as enemies, as other authors have found (Beckett, 1995; Boyd, 1999; Copeland, 1994; Hepburn, 1996; Kearney, 1995; Klee, 1998; Klee, 2002a; Klee, 2002e; Klee and Jackson, 1996; Lewis et al., 1995; Mullings et al., 2001; Powis et al., 2000; Rutman et al., 2000; Taylor, 1993). Studies have shown, however, that a history of drug and alcohol abuse among families is a common factor in the majority of cases of childhood abuse and neglect (Camp and Finkelstein, 1997; Chaffin, Kelleher and Hollenberg, 1996; Forrester, 2000; Hogan, 1998; Jarvis, Copeland and Walkton, 1995; Magura and Laudet, 1996; Nair, Black, Schuler, Keane et al., 1997; NSW Commission for Children and Young People, 2001; Smith and Testa, 2002; Tomison, 1996; Tomison, 2002;
Van Voorhis, 1995). As cases of drug and alcohol fuelled child abuse and neglect feature regularly in the media, it is easy for others to be suspicious of the mothering abilities of women with a history of drug use, particularly IDU, which is an indicator of severe drug dependence and highly deviant behaviour. The consequences of this are that social barriers are erected that deny mothers who use drugs access to the assistance that they need to help them mother well, such as drug treatment programs and other forms of assistance from government social services. In seeking such assistance they reveal their deviant identity as a drug-using mother (or an ex-user) and risk their children being removed from their care. As a deviant, because they use illicit drugs, others assume them to also partake in other deviant behaviours, such as child abuse or neglect (Boyd, 1999).

The types of dangers and harms children of drug-using parents can be exposed to include: poor role models; exposure to drug taking and drug use equipment; exposure to drug dealing; inadequate or overly harsh discipline; neglect; and direct physical and sexual abuse (Barnard, 1999; Barnard, 2002; Barnard and Barlow, 2003; Barnard and McKeganey, 2004; Camp and Finkelstein, 1997; Dawe, Harnett, Staiger and Dadds, 2000; Forrester, 2000; Gough and Lynch, 2000; Hogan, 1998; Kandel, 1990; Klee, 1998; Magura and Laudet, 1996; McKeiganey, Barnard and McIntosh, 2002; McMahon et al., 2002; Schuler, Nair and Black, 2002; Van Voorhis, 1995).

Suitability for motherhood

Morrell (1993) and Holland Baskin and Riggs (1988) highlight how disabled women are often discouraged from having children based upon medical risks and that they may not be ‘good enough’ mothers. Phoenix (1991) demonstrated similar stereotyped expectations of teenage mothers, such as poor perinatal outcomes, child abuse and state dependence.
According to the ideology of motherhood, or ‘the canonical narrative of motherhood’ as described by McDonald (2002), women with HIV are also considered to be unsuitable mothers. As such, they are widely expected to refrain from having children. Along with the stigma associated with HIV, this is based on the negative impact that HIV has upon life expectancy, and the risk of vertical transmission of HIV to the child. Women with HIV who decide to have children are sometimes accused of being immoral and selfish (McDonald, 2002). Women with hepatitis C are likely to be subject to similar stereotyping regarding their mothering abilities based upon their stigmatised and deviant condition (Armishaw and Davis, 2002; Faye and Irurita, 2003; Gifford, O’Brien, Bammer and Banwell, 2002; Hopwood and Southgate, 2003; Zickmund, Ho, Masuda, Ippolito et al., 2003).

Women with hepatitis C may not be considered suitable mothers for a variety of reasons. Firstly, the strong association with, and thus assumption of, IDU implies that such women are of poor moral character, in terms of criminal behaviour, risk-taking and lack of self-control. Women who use illicit drugs are perceived as self-indulgent and selfish, thus making them unsuitable for motherhood due to the self-giving required for good motherhood (Taylor, 1993). Secondly, the health problems created by hepatitis C may prevent them from being a ‘good mother’. Many women with hepatitis C experience from lethargy and often nausea and other more severe symptoms that can limit their ability to carry out their daily activities and responsibilities. Also, that they are at risk of developing serious liver conditions that may be completely debilitating or even lead to an early death poses questions of risk assessment in terms of being able to fulfil their responsibilities as mothers. These health related problems may inhibit their ability to satisfy the requirements, as have been outlined, to be a ‘good mother’. Thirdly, the chance that women with hepatitis C may transmit the hepatitis C virus to their child either during or after childbirth may be
an important consideration for some people. The small proportion of mothers who do transmit the virus to their children may be blamed by at least some people and considered to be irresponsible and selfish. Women with hepatitis C who have children may also be considered irresponsible and selfish, for placing a child at risk of vertical transmission, even if they do not acquire hepatitis C. This blaming of the mother in presenting a risk of infection to her child is likely to be influenced by the stigmas and stereotypes associated with being hepatitis C positive, and for many also being an injector.

**Childlessness**

Hepatitis C may present a range of factors that lead a woman to decide to remain childless, whether they be direct (such as the risk of vertical transmission being considered too great to have children) or indirect, by presenting problems in relationships with partners that will reduce the likelihood of a pregnancy, or reducing the social supports they have available to assist them in motherhood. By remaining childless, these women are more easily identifiable as being deviant. Once identified as deviant because they do not have children, this raises suspicions of further deviance.

Women who contracted hepatitis C through a medical procedure or other source are unlikely to experience these problems to the same degree as women who have acquired hepatitis C through IDU. Although they will likely experience some stigma and discrimination based upon them having the virus, it is likely that women with hepatitis C who have never injected drugs are less likely to suffer the harsh social exclusion that women who have injected or do inject illicit drugs experience. The socioeconomic characteristics of non-injectors with hepatitis C permit them greater social advantages; they
are more likely to have higher levels of education, less likely to experience poverty and be more able to articulate their needs and prevent discrimination.

**If, when and how many?**

Hepatitis C has the potential to be a determinant, or contributory factor, directly or indirectly, in whether or not a woman becomes a mother. It also has the potential to influence when, and how many, children a woman bears. For example, if a woman with hepatitis C already has children, there remains the question of whether or not she should have more, taking into account other factors such as age. Irrespective of whether or not she already has children, hepatitis C may influence the total number of children she bears. A woman with hepatitis C may, for example, decide to have only one child, rather than two because she is fearful that more children may be too much for her to cope with if she becomes sick from hepatitis C. The complexities of the relationship between hepatitis C and the effect it has upon the timing of births, parity and childlessness will be assessed in detail in subsequent chapters.

When a woman should have children is also likely to be influenced by her hepatitis C status. She may be faced with the choice of trying for a baby or beginning treatment for hepatitis C, in which case she must consider which she should do first, or in some cases, she may have to choose between treatment and having a child at that time. She must also weigh up the risk of the treatment being unsuccessful as well as her chances of good health without treatment. For some, earlier motherhood may be beneficial in that the more ‘intensive mothering’ can be completed before the possibility of becoming very sick. On the other hand, treatments of increasing effectiveness and reduced side effects evolve over time. It may be wiser to wait until a more suitable treatment becomes available to reduce
the potential effects of the virus on her health, and then have children. Such a decision is of course going to be determined at least in part according to the woman’s age, for if she is already nearing the end of her childbearing years, then waiting for improved treatments would not be sensible if she has a great desire to become a mother.

**Super-mum**

All women fail in some way to achieve what is expected of the idealistic ‘super-mum’, that is, to provide ‘intensive mothering’, be a ‘good wife’ as well as being successful outside the home usually in the form of a career (Gross, 1998). Based upon the ideology of motherhood, the suitability of women with hepatitis C as mothers is likely to be questioned based on their stereotypical and actual characteristics. There is thus little hope that women with hepatitis C could ever live up to the unrealistic demands of being a ‘super-mum’, particularly given the health and socioeconomic disadvantage they experience. Much of this disadvantage may be explained by their injector status, as injectors are generally of low SES. This social disadvantage is likely to be compounded by hepatitis C through the social and health effects it produces.

**Dealing with professionals**

Becoming pregnant or even thinking about becoming pregnant may bring women to the health professional. It is now well documented that pregnant drug-using women often avoid health care, particularly antenatal care for fear of discrimination and judgemental attitudes and that this can have damaging consequences (Hepburn, 1996; Klee, 2002a; Klee and Jackson, 1996; Klee et al., 2002; McMahon et al., 2002). For many, utilising health care services represents an invitation for interference in, and control over, their lives. Becoming
pregnant, however, can force women into the health care system. Because of the possibility of vertical transmission of hepatitis C, these women may be even more likely to be subjected to invasive monitoring and testing associated with childbearing. In some cases there may also be the automatic involvement of a social worker, based upon the woman’s drug use history. This all leads to confronting questions about lifestyle and moral character, often resulting in feelings of shame and guilt (Klee, 2002a; Klee, 2002b; Klee and Jackson, 1998; Lewis et al., 1995) Naturally, such situations are likely to be avoided where possible. Not attending for antenatal care may, however, result in further negative social labelling.

Oakley (1993) has described how the doctor-patient relationship between obstetricians and pregnant women can be conflicting, when their different perspectives clash, leading to stressful and negative outcomes. For women with hepatitis C, it is likely that this relationship will be under even more strain and thus they will experience further conflict because like the rest of society, medical professionals make moral assumptions and judgements about behaviours. As with other pregnant women, women with hepatitis C may be assumed to be incompetent to make their own decisions during pregnancy, particularly if they are already perceived negatively based upon their IDU and hepatitis C status.

Klee and Jackson (1996) identified some of the fears that pregnant drug-using women have regarding antenatal care, which may provide the reasoning behind poor antenatal attendance and appointment keeping. These fears can include the child being removed from them at birth (Copeland, 1994; Swift et al., 1996) and that their use of drugs would be revealed to others and provoke hostility. These are concerns that are unlikely to occur to most other mothers. Klee and Jackson (1996) found that the fears of these women significantly increased their stress, and that in some cases these fears were justified. Because
hepatitis C and drug use are so closely intertwined, it can be expected that women with hepatitis C experience similar fears and concerns. By avoiding antenatal and related health care these women leave themselves open to criticism and being labelled a ‘bad mother’ (Hepburn, 1996).

**Summary: The social construction of motherhood and women with hepatitis C**

The social construction of motherhood demonstrates the ways in which women with hepatitis C are socially excluded. The very essence of womanhood is based upon motherhood and by limiting their ability to mother and to do so well, society actively marginalizes and excludes many women with hepatitis C through social sanction or by challenging their ability to achieve full female status through motherhood. The doors to career opportunities and other viable social roles are closed to many illicit drug users. Motherhood, however, provides an opportunity in which women drug users feel they can redeem themselves and become a ‘respectable woman’ (Murphy and Rosenbaum, 1999). Motherhood, for many women, is a means of establishing themselves in society. For women with few life options, motherhood is a socially acceptable role they perceive they can be ‘naturally’ good at, unlike many other social roles (Bedimo, Bessinger and Kissinger, 1998). When the many social controls and sanctions that childbearing is subject to are considered, motherhood may not facilitate such a new identity and social position. this may not necessarily be the case for women with hepatitis C.
Section 2: Research Methods

This section contains just one chapter, on research design and methods. In this chapter, the design of the research and the methodological tools employed are described in detail. Also, the realities of conducting research with women who inject illicit drugs are discussed.
Chapter 6: Research Design and Methods

This is a qualitative study of childbearing and the social construction of motherhood among women living with hepatitis C. The thesis focuses on women’s lived experiences of the ways in which hepatitis C affects childbearing decisions and motherhood experiences. It is a primary objective of the thesis to present the multiple realities of women living with hepatitis C and to do so from their perspective, and where possible, using their own words. It is a descriptive study of the lived experience of women’s everyday lives. The research design and specific methods of data collection, sampling and analysis have been informed by a mix of qualitative approaches and techniques, in order to meet the aims and objectives of the thesis. This chapter describes the methodological approach of the study, the research setting, tools of data collection, sampling strategy, data analysis and concludes with a discussion of the ethical and logistical issues that arose during the research process.

Methodological approach

Within the paradigm of qualitative research, there are many different methodological approaches. The appropriate use of each approach depends upon the aims of the research and the theoretical foundations of the mode of inquiry. The initial aim of this thesis was to explore an issue about which there was very little existing literature and where almost no research had been conducted. As such, it was a requirement that the research design permit exploration of the issue, without imposing preconceptions or theoretical frameworks.

The research question was initially focussed upon the impact that living with hepatitis C has upon childbearing decisions of women living with the virus, in terms of parity, timing and childlessness. With this question in mind, it was initially an exploratory study as there was
no existing literature to indicate how living with the virus may impact upon childbearing decisions. It was essential that a flexible research design be employed in order that new directions in the research question were accommodated. A grounded theory influenced approach was used in order to explore the issues.

**Grounded theory**

The grounded theory approach is traditionally associated with the work of Glaser and Strauss (1968) and later Strauss and Corbin (1998). Also known as the constant comparative method, this approach involves starting the research from an exploratory position. As issues and themes become apparent during data collection and preliminary analysis, the research question became refined for subsequent data collection.

The aim of pure grounded theory (Glaser and Strauss, 1968) is to produce theory, through the process of constant comparison. This was not the aim of this thesis. I did what Glaser (2002) describes as a ‘partial grounded theory’, in that I used the approach to generate new understandings of women’s self perception in relation to motherhood whilst living with hepatitis C; a chronic, infectious disease. This thesis does not create theory, rather, as issues and themes became apparent during data collection and preliminary analysis, I turned to existing social theories and explored their potential use in explaining the issues highlighted in the data. Analysis of the data involved elements of the grounded theory approach, such as constantly comparing women’s experiences, narratives and constructs using the coded data (Charmaz, 2000). Existing theories were used to refine the research question, once the salient issues had been introduced in the initial interviews. Theories then provided boundaries for comparison of the data, from which patterns and explanatory relationships were established (Morse, 1998).
I had no clear preconceptions about exactly what issues would be raised by the women, nor what kind of responses would be generated, thus the grounded theory approach was highly appropriate. Grounded theory permitted refinement of the research question as the relevant issues became apparent. Through this process, the direction of the research was constantly refocussed and refined.

It became evident in the initial data collection that the original research question, on how hepatitis C impacts upon childbearing decisions, was only part of a broader research question of spoiled identity and the social construction of motherhood. Thus this specific question was only a component of a much bigger issue and unless the bigger issue was addressed, the findings to the original research question would lack contextualisation, meaning and value. The flexible design of the research and the tools used permitted the focus of the research question to shift considerably.

**Research setting: Context**

Semi-structured interviews were conducted with 34 women living with hepatitis C in Sydney where I was employed at the National Drug and Alcohol Research Centre (NDARC). I worked on several different projects conducted by NDARC over a period of three years, concurrently to conducting research for this thesis. During this time, I conducted structured and unstructured interviews with injectors, health service providers and law enforcement personnel in open-air drug markets, such as Kings Cross, Cabramatta and Redfern, as well as rural areas.

During my employment as a research officer at NDARC, I spent many hours recruiting participants and conducting interviews in primary care services that target street-based
injectors, methadone clinics and needle and syringe programs. As I became familiar with injectors and service providers, they too came to see me as a familiar and trustworthy face. Through working with all these different people, I gained many different perspectives on the issues surrounding IDU and hepatitis C.

It was through this work that I became immersed in the IDU world of Sydney. Although the research for this thesis was conducted separately from my employment at NDARC, becoming immersed in the field in this way allowed me to establish a sense of trust and rapport with the women I interviewed for this thesis, and the services that assisted with recruitment. Living in Sydney and working in the drug and alcohol field greatly facilitated recruitment into this study and enabled me to establish rapport in ways that would have been very difficult had I not been introduced to the field in this way. Having this working knowledge and experience also provided contextualisation of the interview data. I established positive working relationships with drug and alcohol service providers and their clients, as well as the police.

**The research setting and establishing rapport**

Women who inject illicit drugs are generally suspicious of others, particularly those who ask questions about their drug use and their children in particular. Because injecting illicit drugs is subject to criminal sanctions, they fear being arrested, or having their children removed from their care, amongst many other threats. Many of the women injectors I spoke to and interviewed during fieldwork reported having had their children removed from their care, largely because of their drug use. Additionally, because hepatitis C is stigmatised, the threat of having their hepatitis C status revealed to others further fuelled their suspicion. Even for
women who had never injected, there existed risks associated with others discovering their hepatitis C status. Women who deal with these sorts of risks on a daily basis are suspicious.

I had not previously met many of the women before conducting the interview with them. However, many of them had friends and associates whom I had interviewed for this study, as well as a range of different NDARC projects. Having been assured of my trustworthiness by a friend or acquaintance assisted in building a good rapport, which ultimately leads to more credible research, for if the participant feels they can trust the interviewer, they are more likely to provide truthful data (Minichiello, Aroni, Timewell and Alexander, 1995). This sense of rapport was essential in discussing personal and sensitive topics as IDU, having children, motherhood and hepatitis C. The strategies I used to develop rapport with participants are discussed in detail later in this chapter.

**Research setting: Position of the researcher**

It is widely accepted that there is no such thing as value free inquiry. Values are inherent in all forms of scientific inquiry (Caelli, Ray and Mill, 2003; Denzin, 1994). These values represent the paradigmatic underpinnings of the research, and so influence the ultimate aims of the study and the representations made. Values are different from bias in that values are an essential guiding element of scientific inquiry. Biases, however, should be identified and where appropriate, controlled for in order to avoid producing misleading results and interpretations (Ezzy, 2001). In quantitative research, issues of bias are at the heart of the quality of the research and methods of eliminating bias are employed. Within qualitative research, rigorous interpretation is sought in order to manage the effects of bias (Altheide and Johnson, 1994; Guba and Lincoln, 1989; Lincoln and Guba, 1985; Miles and Huberman, 1994; Morse, Brarrett, Mayan, Olson et al., 2002). The social processes through
which interpretations are identified and acknowledged are made explicit, rather than attempting to remove them. It is recognised that bias driven by class, race, ethnicity, and culture can never be totally removed from inquiry (Denzin and Lincoln, 2000; Patton, 1982). The strategies adopted to ensure rigour within this thesis are discussed in detail later in this chapter.

A reflexive approach was adopted, in which it is acknowledged that the researcher is part of the setting, context and culture in question (Altheide and Johnson, 1994). I identify and acknowledge the ways in which my own personal characteristics and preconceptions may have had upon the research (Miles and Huberman, 1994), as is the case for any researcher (McCaslin and Wilson Scott, 2003). This continual process attempts to identify the ways in which the researcher might have impacted upon the research, through their preconceptions, biases and social identity.

The multiple realities of the women in the sample are presented as authentically as possible. The findings are presented from the perspectives of the women in the study, and where possible, in their own words. However, this is ultimately my interpretation of what participants told me, and what I observed, as it is impossible to be an entirely neutral observer (Caelli et al., 2003) and the fact that the interviews were very much a result of the interactions between myself and the women. The data I obtained from every participant was influenced by trust and rapport, the effect of my presence, only having a short relationship (one interview) with most participants, the relative status of myself to the participants, and the context in which the interview took place (Silverman, 1993).
Interviewing

In approaching the interviews with women with hepatitis C, I was apprehensive about how I might be perceived by many of these women. I was concerned about how most of these women, who I anticipated would be mostly of lower SES, who were current or past injectors, with lower levels of education, would respond to my questions based upon my social identity. My social identity, that they would have at least initially perceived, would be of a white, educated, middle class young woman conducting research for a university. During the course of the interview, however, they discovered other aspects of my social identity, such as that I was single, childless and from the UK. I was always careful to dress appropriately for interviews. When interviewing street-based women in Kings Cross for example, I ensured I was dressed casually.19 For other women, however, more formal clothes were appropriate, such as when interviewing women at the office where they worked. Some women asked specific questions about my social identity that were of particular importance in their assessment of my social identity. For example, some women asked if I injected, or how I came to be doing such research. I expected that some of the women, particularly very marginalised, street-based women, may not speak freely to me because of these personal characteristics. However, this was very rarely the case. As anticipated, my working-class background proved to be beneficial in being able to relate to some women in being able to express empathy through understanding and to some degree, shared experience. As I shared information about myself throughout the course of the interview, they appeared to relax and offer more personal information of their own.

19 I also ensured that I did not wear any expensive looking jewellery, or carry items such as a laptop for such interviews. This was done not only for the sake of appearances, but also to reduce the risk of robbery, as specified in the NDARC interviewer safety protocol (Day, Topp, Swift, Kaye et al., 2002b).
Analysis and interpretation

Throughout the research process and my NDARC work experience, I developed a sense of advocacy for the women in the study. This no doubt influenced the analysis and write-up of the research, despite my efforts to reduce the effects of this bias. In order to try to deal with this bias, I consulted other researchers, some of whom worked within the drug and alcohol field, and others independent of this research topic. By including those working in drug and alcohol research, insight and experience into the specific issues were sought. However, like my own perspective, theirs were also likely to be influenced by an advocacy agenda. Their feedback was then assessed from a more independent perspective, by those with little or no knowledge of the issues involved.

Methods of sampling

A maximum variation sampling strategy (Hudelson, 1994; Miles and Huberman, 1994; Morse, 1998; Patton, 1982; 1990) was employed. The aim of the maximum variation sampling strategy is to obtain a deliberately heterogenous sample, facilitating examination of commonalities within the sample (Morse, 1998). This strategy permits exploration of variations, as well as the commonalities that cut across the sample (Hudelson, 1994). Variation within the sample is determined according to a number of dimensions, or characteristics (Morse, 1998; Patton, 1982). In this sample, these dimensions included age; current or past injector; drug dependency; occupation; being pregnant; having existing children; childlessness, and social exclusion. These dimensions were used to facilitate the creation and description of sub-groups that emerged within the data. Extreme cases, as well as typical cases, are included in this sampling strategy. An extreme case in this thesis was for example, a street-based sex worker. These women were classified as extreme in relation...
to their social exclusion, which was one of the dimensions identified within the sampling strategy.

**Selection criteria**

The selection criteria were that participants must be female, have chronic hepatitis C, and be of childbearing age (roughly 18-45). The selection criteria were very open so that it was possible to include women with particular characteristics (dimensions) in order to achieve a maximum variation sample. For example, it was highly desirable to include some women who were pregnant and who had recently given birth, in addition to women who had never been pregnant, and those who had children. This was possible through the use of a flexible research design and sampling strategy. Additionally, once it became evident that the issues surrounding hepatitis C among drug-dependent street-based women had been adequately covered (through saturation of the data in regard to this particular dimension), recruitment was refocused upon women with other characteristics identified as dimensions within the sampling strategy.

Using the grounded theory approach, the dimensions of the sample were refined throughout the data gathering process. For example, initial data indicated that hepatitis C created different issues for drug-dependent women than for those who had never injected drugs. The recruitment strategy was adjusted to ensure that several drug-dependent women were included in order to explore this issue through internal comparison.

The description of the sample in the next chapter of this thesis demonstrates that this sampling strategy was successful in obtaining the perspectives of a wide range of women. Although no claims of generalisibility to the wider population of women with hepatitis C
are made (as it would be inappropriate given the small sample size), the distribution of characteristics (dimensions) of the sample are very similar to a large sample of women with hepatitis C in Australia (Gifford et al., 2003).

**Methods of recruitment**

To achieve a maximum variation sample required the use of several different recruitment sites and methods. Each of these is described in detail below.

To access a broad range of women with hepatitis C, the research was featured in the Hep C Review, a quarterly publication produced by the Hepatitis C Council of NSW aimed at people living with hepatitis C. The magazine has a broad readership and so provided access to some of the less visible, harder to reach participants that could not be recruited through needle syringe programs and other health services. As well as subscriptions, the publication is distributed throughout drug treatment services, prisons and through drug user support groups. After recruitment had been slower than anticipated, a flier was inserted into another issue of the Hep C Review, but the response to this was also disappointing. This strategy did, however, access a broad range of women with hepatitis C, including women who had never injected, who were actually more difficult to access than current or past injectors.

A severely marginalised woman in Kings Cross was recruited through the Hep C Review advertisements. She introduced me to several other similar women in and around Kings Cross, who were drug dependent and doing sex work. It would have been possible to recruit many more women with similar characteristics in this way. However, the sample became saturated with participants with such characteristics, and this recruitment strategy
with this group of women was halted. Several other women, with varying characteristics were also recruited through word of mouth.

Although the research design was flexible enough to accommodate changes in recruitment strategies, the human research ethics committees (HRECs) that restrict the use of different recruitment strategies and sources were not. This is discussed in detail later in this chapter.

The other sources of recruitment that were used included an inner city hospital gastroenterology department and antenatal care unit, and an inner city needle and syringe program. Fliers and posters were distributed within these services. Within the gastroenterology department and the antenatal unit, I would attend on days staff recommended, when they expected I would be able to recruit. In both departments, hospital staff approached eligible women on my behalf and asked them if they would be willing to speak to me, without having to commit to anything, so that I could explain what participation would involve. Most women agreed and the interview was conducted after they had seen the doctor, at the gastroenterology department, where a room had been made available.

Such a room was not available at the antenatal unit due to a lack of space. Women recruited there were provided with an information sheet about the project and we exchanged telephone numbers so that a suitable time and place to conduct the interview could be arranged. Additionally, the women attending the antenatal unit were often there well over an hour (over three hours in some cases) in order to have a barrage of tests and consultations. Consequently it was not appropriate or feasible for me to ask them to do the interview at that time. This meant that some of the people recruited in this way were lost.
before they were interviewed. It was often impossible to contact them by mobile phone and given the sensitive nature of the research, messages were not left with other people.

As was the case with many of the women recruited through all sources, even after confirming the appointment with them the day before and on the day (where possible), many women simply did not show up. Additionally, a large proportion of the women who did show up for interview were often over half an hour late. This appears to be a significant problem when conducting drug and alcohol research, and was not exclusive to my study, as I found during my work at NDARC. This is not because illicit drug users are rude, or necessarily disorganised. As Taylor (1993) highlighted in her study of women injectors in Scotland, although their lives may appear chaotic, in fact they have to be carefully planned in order to maintain their drug use. They have to obtain money for drugs, get the drugs, and acquire injecting equipment in addition to their other responsibilities including mothering and attending appointments with social workers, methadone prescribers, and so on. It is more likely that the women in this study who did not turn up for interviews had to prioritise another aspect of their life over the interview, rather than just not caring to show up.

Participants were each reimbursed $25 towards travel costs and other inconvenience they may have experienced as a result of participating in the research, for which they were required to sign a receipt. In Australia, the use of participant payments has become standard practice in drug and alcohol research. I was advised by several sources of recruitment that unless I was offering some form of payment, it would be very difficult to recruit participants. That is not to say that financial incentive was the primary motivation for participating in the research. Fry and Dwyer (2001) reported that motivations for participation among injectors are rarely only driven by economic gain and are usually multi-
faceted. Participant payments simply made it easier to participate, and represented genuine appreciation for their time and effort. The women were not asked about their reasons for opting to participate in the research, though many offered this information. Some women reported altruistic reasons for participating. They wanted others to understand the issues they faced, and hoped that in sharing these experiences, things might eventually change through understanding. Some women, particularly those with little social support, reported after the interview that it had been good for them to be able to talk to someone about these issues openly, with a promise of confidentiality (as far as is possible) and importantly, not to be rushed. More to the point, they appreciated someone listening to them in a non-judgemental way. I only ever conducted a maximum of two interviews a day, and usually only one. This meant that the length of the interview was not restricted, nor was the time I spent with participants after the interview had officially ended. This is in contrast to much structured interviewing of injectors, in which several people will be interviewed in a day.

Methods of data collection

Semi structured interviews were employed as the principal research tool for this thesis.\(^{20}\) It was important to establish rapport very early in the interviews in order for the interviewees to become comfortable enough to be able to discuss with me some very personal and sensitive topics. This was especially important because I was to only have one opportunity to interview them. I expected this to be particularly important when interviewing the street-based sex workers in Kings Cross. With these women it was essential to appear non-judgemental throughout and to establish this at the beginning of the interview. To do this, upon meeting the women I would have a brief, non-intrusive chat before beginning the interview proper (Minichiello et al., 1995). This would usually begin with quite casual,

\(^{20}\) See appendix 10 for copy of the interview schedule.
chatty conversation, in which I would provide some information about myself that could be important in the way they develop an impression of my social identity.

Additionally, speaking so freely made the participants more relaxed as they came to realise that the interview would not be as formal as many of them imagined. During this time, I also explained what the research was about and what kinds of questions I would ask, emphasizing that most of the interview would take the form of a conversation, rather than a series of questions and answers which I would tick off on a form, which was what most of them expected. In addition to a range of other information I provided at this stage, such as who was funding the research and where the results may be published, I provided opportunities for the women to ask questions before we began, as recommended by Wright et al (1998). While some asked questions about the nature of the research and who was funding it, many asked more personal questions, such as how I came to be doing such research, what it is like to live in England and questions about my family and so on. In answering such questions and offering some personal information, I established a good rapport early on, so that they were then more comfortable revealing sensitive information to me later in the interview.

The initial interviews were broad in nature, as Morse (1998) reports is standard practice in studies that have an exploratory component, such as this thesis. Participants were permitted a high level of autonomy in determining the direction of questioning. Although all interviews remained flexible, subsequent interviews, informed by the data from previous interviews, were more focused, as the research questions became more refined. Themes and associations made based upon preliminary analysis were refined in subsequent interviews.
Each interview lasted between 40 minutes and two and a half hours, and most of the interview was recorded on audio cassette, and was later transcribed verbatim. Notes were not made throughout the interview, as although these can be very useful (Minichiello et al., 1995; Wright et al., 1998), it was felt the importance of maintaining a good rapport was a greater issue for data quality, than the loss of any data that may not be recorded. As Britten (1995) recommends, notes were made immediately after the interview where possible. These notes contained details of the interaction that would not have been evident on a transcript of the interview. Information such as appearance, indications of anxiety, or the presence of a partner or children was noted. Some associations that would be worthy of exploration with other participants were also noted. For example, one woman explained to me that she was concerned about her future hepatitis C related health and that this was a factor in her childbearing decisions. These data were also in the transcripts, but the notes were immediately more accessible as there was a delay between the interview and having the audio cassette transcribed. These notes were then used to help reframe and focus the research questions for subsequent interviews, and directed reading of existing literature.

At the beginning of the interview I introduced myself and the research topic, explaining who I was, who was funding the research and the purpose of the research. It was explained what was of interest to the research, and what kind of questions participants would be asked in the interview. The first part of the interview involved completion of a short demographic questionnaire, which contained some short closed-response questions relating to IDU and hepatitis C. During the questionnaire, participants often began to ‘tell their

\[\text{21 The data were ‘cleaned’ before being presented in the write up; data were spellchecked; names and identifying information removed or changed; and some were ‘tidied-up’ to make them more readable, but efforts were made to ensure that this did not impact upon the meaning of the statement (Morse, 1998).}\]
\[\text{22 See appendix 9 for a copy of the questionnaire.}\]
story’ and so for most participants, this section of the interview was recorded on audio cassette, along with the main, semi-structured interview.

There were multiple purposes for conducting the questionnaire at the start of the interview. Firstly, it provided background information on each participant that would facilitate some comparison within the sample, in for example, identifying sub-groups. These data have also been used to compare the characteristics of this sample with other samples of women with hepatitis C (although not to make generalisations). Secondly, the questionnaire was used as a starting point. It provided a place to begin discussing many of the issues. Thirdly, the information gained in the questionnaire was used to inform more specific questions in the semi-structured interview. It was also used to cross-check, or contextualise information provided in the semi-structured interviews.

Once the questionnaire was completed, it was explained that the rest of the interview would be very different and more like normal conversation. Thick descriptive and contextual data was required to be able to meet the aims of the research. It was emphasised that they should discuss whatever they felt was relevant to the issue at hand and participants were encouraged to go into detail in explaining their feelings and experiences.

If my opinion was asked, I gave it, as did Reid (1991). It was felt necessary to maintain a good rapport within the interview because the topics being discussed were so sensitive. Being able to ask questions in this way provided the participant with a greater sense of autonomy within the interview. There were instances in which I was asked specific questions that I did not wish to answer at that point in the interview. These were on topics that I was interested in asking of the participant first, such as ‘what is the risk of vertical transmission of hepatitis C?’ It was important for me to assess their knowledge regarding
this issue, so when this occurred, it was requested that this be discussed later in the interview, as if they were given this information at that point of the interview, it would ‘contaminate’ some of the responses that were of particular interest to the research question. Participants were given the opportunity to ask me whatever they liked at the end of the interview.

In a small number of cases, it appeared that the interviewee was not comfortable talking about sensitive issues, possibly because of the presence of the tape recorder. When this happened, I took time to go over the issues raised after the interview had officially ended and the recorder turned off. On these rare occasions, the interviewee would open up and engage in a lengthy chat about some of the issues that were raised in the interview but also new issues that they felt more comfortable discussing in a less formal situation. After saying goodbye to the participant, notes were made on some of the additional things discussed off tape, which like the other notes, were used to inform future interview questions and reading.

Most women appeared to be comfortable discussing these very sensitive issues. In fact, their frankness was often surprising. Most interviews were conducted with the women alone in order to provide an environment in which they would feel comfortable discussing sensitive information (Helitzer-Allen, Makhambera and Wangel, 1994). There were times when this was not possible and other people were present, such as their partner or children. Similar to the experiences of Wright et al (1998), when present, their partner often added information and raised interesting issues throughout the interview. Some questions, such as those on abusive partners, were, however, omitted.
Like any other social event, an interview is a form of social interaction (Suchman and Jordan, 1990), which must be defined by the research protocol. Wright et al (1998) advocate that it is important to define boundaries surrounding the role as a researcher and to make provisions to permit this role. For example, if the researcher considers the role of providing support and information to their participants, then they should ensure that they have the appropriate skills, knowledge and resources to be able to do so. I provided participants with hepatitis C information resources from the Hepatitis C Council NSW. I encouraged the women who appeared to be confused regarding their hepatitis C to contact the Hepatitis C Council for more information and support at the end of the interview.

Interviews were ended by thanking the respondent for their time and willingness to speak to me so openly. They were reassured of the confidentiality and value of the information they had shared. I often stayed for a while and had another coffee while we chatted in a less formal manner. This allowed participants to ask further questions about the research, hepatitis C and me, the researcher. It was at this time that we discussed issues that had been delayed until the end, such as their questions regarding the risk of vertical transmission.

Wright et al (1998) report that encouraging self-analysis in interviews such as these may promote protective behaviour but may also incite guilt (especially regarding their children). Extra time was spent with those women who appeared to be upset or in any way distressed or confused about the issues discussed in the interview, to ensure that they were alright and knew where to go for further information and assistance. A small number of women became upset during the interview. When this occurred, they were asked if they wanted to

23 A Hep C Helpline card (produced by the Hepatitis C Council NSW); ‘Hepatitis C, what you need to know’ booklet (Hepatitis C Council of NSW, 2000); ‘Women and hepatitis C’ booklet (Australian Hepatitis C Council, 2000).
stop the interview, but no-one did want to stop, they insisted on talking through the issue that had caused them to become upset. Kellehear (1989) reported a similar, though more intense, experience when his research subjects became distressed discussing their terminal illnesses. Like the people in Kellehear’s study, the women in this study valued being heard, and listened to, over and above their immediate distress. As Kellehear (1989) reports, the ethical considerations surrounding research such as this are not black and white.

**Location of interviews**

Interviewing illicit drug users has been identified as potentially risky (Day and Topp, 2003; Wright et al., 1998). I followed a safety protocol that was specially designed for use when interviewing illicit drug users (Day et al., 2002b).24 Interviews were conducted at a time and place convenient to participants. Most of the women in my sample were most comfortable being interviewed in their own homes, as has been found in other similar research (Wright et al., 1998). Unfortunately, the safety protocol I followed, (Day et al., 2002b), did not permit this, except in circumstances where an alternative was not suitable. Some interviews were conducted with women in their own homes where they were too sick to come to another location or could not leave because of childcare responsibilities.

It appeared that women who were interviewed in their own homes or in other places that they nominated, such as a café, offered more information than the women who were interviewed in health care settings, such as the hospital. In particular, those women

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24 This included advising someone of where I was going, who I was going to meet and when I could be expected to return. I always carried a mobile phone and only interviewed in locations I considered to be safe. I did not experience any kind of threatening situation in any of the interviews I conducted for this thesis. When I conducted interviews in participants’ homes, I was always made to feel extremely welcome and as comfortable as possible, and was always offered a drink. When interviewing participants in cafes or other public places, this courtesy was returned, and we conducted the interview over drinks, and sometimes a snack as Morse (1998) suggests.
interviewed in their homes offered more contextual information, and thick descriptions of events and emotions. These women appeared to be more comfortable in their own space, without any prying ears or other potential threats. The women interviewed at the hospital tended to offer short, often dichotomous responses. In the hospital environment, participants behaved more like a patient, assuming I had some medical authority, despite being informed otherwise. Wright et al (1998) also found that better information was elicited when interviews were conducted in participants’ homes, where there was an increased sense of trust and a clear distinction made between the researcher and the health or other services through which participants were recruited.

None of the women interviewed were heavily intoxicated, as is sometimes a problem when conducting drug and alcohol research (Marsh and Loxley, 1992; Wright et al., 1998). Some of the women interviewed had injected or been drinking on the day of the interview, but none of them were intoxicated to the point where it impacted significantly upon the interview. To have excluded the women who had used drugs or been drinking prior to the interview would have meant excluding the ‘extreme’ cases purposely included in the sampling strategy.

**Methods of analysis**

The data were analysed thematically, according to the process described by Aronson (1994), which is similar to that of Miles and Huberman (1994) and Minichiello and Stynes (1995). Within thematic analysis, the themes that arise from the data are brought together and contextualised and in doing so become meaningful (Aronson, 1994; Minichiello and Stynes, 1995). Within the analysis conducted for this thesis, there was also consideration of
difference (Minichiello and Stynes, 1995), in order to account for the variation, as well as commonalities, that exist between sub-groups within the sample.

Interviews were transcribed as soon as possible after the interview in order that the interview data were used to refine the interview questions and directions for subsequent interviews. The transcripts were all read and re-read throughout the data collection and analysis processes. In line with the grounded theory research strategy, analysis was begun early, after conducting only a few interviews (Glaser and Strauss, 1968; Strauss and Corbin, 1998). Some key concepts and themes were identified within this early data, and preliminary thematic codes applied to the data. These key concepts informed the further direction of the research. These concepts and issues included stigma, IDU, symptomology, risk perception, ‘good motherhood’, and age. Analysis was inductive, rather than imposing a framework on the data (Patton, 1982); the patterns, themes and categories emerged from the data, rather than a theory framework.

Subsequent data collected was analysed in relation to the concepts and patterns established in initial interviews. This is similar to the grounded theory strategy. Using the data continuously being collected, these concepts and patterns were refined. As further data was collected, the coding scheme was continually updated. The patterns and codes were then collated to produce sub-themes. At this stage, some of the ideas, and sub-themes were presented to participants within the interviews, and their feedback incorporated into the further refinement of the concepts and patterns. Finally, sub-themes were examined in relation to existing literature and theories. In this thesis I turned to the literature that existed on deviance and stigma, the social construction of motherhood, gender and illicit drug use, and women’s social experience of hepatitis C.
The data was coded using a hierarchical thematic coding scheme, which permitted searching of the data in varying degrees of detail. This type of coding is particularly suited for large complicated datasets (Gifford, 1998a). Thematic categories are identified by unique codes. Groups of these thematic codes, or umbrella codes are also identified using unique codes. The meaning of each code is detailed in appendix 11 and the hierarchical position of each of these in appendix 12.

The transcribed interview data were analysed using *The Ethnograph* (Seidel, 1998), a computer software programme designed to assist the analysis of qualitative data. *The Ethnograph* is particularly well suited for application in the grounded theory approach (Charmaz, 2000). In qualitative analysis, computer software does not run the analysis, it merely facilitates the process and makes it more efficient (Gifford, 1998a; Lwando-Hundt, Beckerleg, Alem and Abed, 1997; Richter, 1993).

The data were coded using a hierarchical scheme, which permits searching and analysing at different levels of detail, particularly when the data are complex (Willms and Johnson, 1993). ‘*The Ethnograph*’ proved very efficient in doing this and was particularly useful in searching for data with multiple codes. For example, searching for data which had been coded as both ‘stigma’ and ‘IDU’.

Analysis continued throughout the writing-up process, continually referring back to the transcripts and the data that had been sorted into sub-themes. As Minichiello (1995) reports, the analytic and writing-up processes in qualitative research are inextricably intertwined.
The questionnaire data were entered into a database upon return to the office from the interview. These data were constantly checked to monitor the characteristics of the participants, in order that recruitment was aimed accordingly in order to obtain a sample of maximum variation. These quantitative data were later used to summarise the characteristics of the women, but no statistical analyses were performed on it. These data are summarised in table format in chapter seven. The quantitative data were also used in the analysis of the qualitative data, to assist in allocating women into sub-groups for internal comparative analysis.

**Rigour**

Quantitative research has a finely tuned barrage of methods and criteria to evaluate the rigour, or quality of research. These methods and criteria are readily transferable within quantitative research. Qualitative research cannot be evaluated using the same strategies because of the several different paradigms (basic belief systems) within which qualitative research is conducted (Krefting, 1990), and the very different aims of qualitative research to most quantitative research. The methods and criteria on which qualitative research is judged must be appropriate to the aims of the research. It has been argued that the traditional terms of ‘validity’ and ‘reliability’ are not appropriate to much qualitative research (Altheide and Johnson, 1994; Guba and Lincoln, 1989; Lincoln and Guba, 1985). There are a series of principles to establish rigour within qualitative research, on which there exists a sizable literature. The methods and criteria for ensuring rigour in this thesis were determined by the aims of the thesis.
Strategies of verification

Strategies of verification, as described by Morse et al (2002) were adopted in order to ensure the research was rigorous. Several methods were used to ensure the quality of the data and the findings (Guba and Lincoln, 1989; Lincoln and Guba, 1985; Miles and Huberman, 1994), in addition to the overall strategies outlined by Morse and colleagues (Morse, 1998; Morse et al., 2002). These were used throughout the research process, and influenced the direction of the research. These strategies of verification are based upon the research process being iterative. An iterative research process ensures that the research is constantly being assessed in terms of congruence between the research question, methods used, literature drawn upon and the analysis conducted. In continually ensuring goodness of fit of these components of the research, flaws that might otherwise persist throughout the research process are identified and dealt with (Morse et al., 2002). This constant assessment of congruence fits closely with the principles of grounded theory, in which emergent themes are constantly verified and refined using further data collected (Glaser and Strauss, 1968; Strauss and Corbin, 1998).

Each of the strategies of verification outlined by Morse et al (2002) are addressed below, and the specific methods that were used in order to verify the findings outlined.

Methodological convergence: As described above, the methods used, along with other components of the research, were continually assessed to ensure they were appropriate to the research question.

Appropriate sampling strategy: In qualitative research, the sample must be representative in terms of an experience, in this case, hepatitis C, rather than being demographically
representative of the general population, as is usually the case in quantitative research (Morse, 1998). The sampling strategy for this thesis was outlined earlier in this chapter.

Saturation must be achieved, where further data collection produces replication of existing data. Adequacy of data refers to the amount of data collected, rather than the number of people data are collected from, as is the case in quantitative research. The criteria to assess whether one has done enough in qualitative samples, is different to that in quantitative samples. Rather than focussing upon the number of participants, as in quantitative research, the concept of saturation is often used in qualitative research. What exactly constitutes ‘saturation’ is, however, unclear (Caelli et al., 2003). Within this thesis, saturation is defined as having accounted for and understood variation. Further data collection achieves only repetition (Morse, 1998). This is appropriate given the maximum variation sampling strategy. Initially, it was expected that about 25 interviews, or thereabout, would be sufficient to account for and understand variation among women with hepatitis C. However, once this number of interviews was reached, it was evident that this was insufficient. The final sample size was 34 women. Once the sample approached this size, as Morse (1998) describes, the data began to repeat from previous interviews, to the point that they were no longer adding any further insight. Data collection then ceased.

Collecting and analysing data concurrently: As described above, data collection and analysis were conducted concurrently. This led to the modification of the research question and the literature that was drawn upon to further focus the thesis.

Active analytic stance: Member checks were performed, in which ideas and concepts that had emerged from the data were presented to other participants for their feedback. This
enabled refinement of concepts and themes and increases the credibility of the findings (Guba and Lincoln, 1989; Lincoln and Guba, 1985; Morse, 1998).

In a similar manner to member checks, peer debriefing (Guba and Lincoln, 1989; Lincoln and Guba, 1985) was also conducted. This involved discussing the categories, themes and conclusions with impartial colleagues. Through this process the credibility of the emergent concepts and themes was constantly appraised.

Once all the data had been coded, they were left for several weeks, while another task was completed. The data were then recoded, and the coding schemes compared. There were no significant differences in the way that the data were coded on separate occasions, resulting in a dependable coding scheme (Guba and Lincoln, 1989; Lincoln and Guba, 1985).

In acknowledging some of the possible effects of the situation in which data and other contextual information, such as researcher characteristics, were gathered, it is possible to weight the evidence (Miles and Huberman, 1994). This involves placing more value on some of the sources of data than on others. Some of the situations in which participants appeared to offer ‘better’ information, such as when they were interviewed in their own homes, rather than in a health service setting, have been highlighted earlier in this chapter.

**The audit trail:** The methods of data collection, analysis and interpretation have been outlined explicitly, in order that another person may determine how repeatable the research is, or whether the situation was too unique to replicate (Guba and Lincoln, 1989; Lincoln and Guba, 1985).
A rich description of the sample characteristics is provided in both the text of the thesis and the appendices. This enables others to determine whether or not the findings have wider applicability in other context specific situations (Guba and Lincoln, 1989; Lincoln and Guba, 1985).

The utilisation of the study was also considered in evaluating the quality of the research (Miles and Huberman, 1994). The findings of the study are considered in terms of policy in chapter eleven. The ways in which the knowledge gained from the thesis may be used to improve the lives of women living with hepatitis C are explored and suggestions made.

**Triangulation**

The process of triangulation involves approaching the same question, or problem from more than one perspective. Triangulation strengthens the findings of research by arriving at similar conclusions from these different perspectives (Gifford, 1998b; Miles and Huberman, 1994; Morse, 1998; Morse et al., 2002; Morse and Chung, 2003; Patton, 1982). This results in the research being more holistic, which is a primary aim of qualitative research (Morse and Chung, 2003). There are four main types of triangulation: data; method; researcher; and theory (Gifford, 1998b). Several forms of triangulation were used in this thesis. Each of these are discussed below.

**Methodological triangulation:** Use of more than one method provides different perspectives of the same research question (Morse, 1998; Morse and Chung, 2003). In this thesis, qualitative data were obtained through semi-structured interviews. This was supplemented with the use of a short questionnaire.
Theoretical triangulation: Several different theories were drawn upon in order to inform the analysis of the data and to explain some of the processes and relationships identified. These included deviance, stigma, and the social construction of motherhood.

Data source triangulation: For every claim in the thesis, there are at least two converging sources of data (Guba and Lincoln, 1989; Lincoln and Guba, 1985; Miles and Huberman, 1994). The maximum variation strategy provided many different perspectives, through which commonalities, as well as variations, were identified. The findings of this thesis were also compared to the findings of studies with similar samples, examining similar issues, such as those of Gifford et al (2003) and Platt and Gifford (2003).

Data type triangulation: Some quantitative data were also collected in the form of the short questionnaire. This was used to cross check information gathered in the semi-structured interviews (Miles and Huberman, 1994). This may also be interpreted as a form of methodological triangulation, as described above.

Ethical and logistical issues

Ethical issues

There were several ethical issues that were taken into account in this study. Many ethical issues arose because most of the women identified in the sampling strategy were current or past injectors, and as such there was a possibility that they may discuss illegal behaviours during the course of the interview. In addition to ethical issues concerning confidentiality and participant payments, there are potential legal problems involved in researching this population.
Because the research topic under question was very sensitive and highly stigmatised, it was important to provide the reassurance of confidentiality to participants. Due to legal reasons, however, researchers cannot offer a guarantee of confidentiality (Fitzgerald and Hamilton, 1996). This was particularly important when discussing drug use, especially when discussed in regard to the women’s relationships with their children. Many of the women interviewed had experienced problems with the Department of Community Services (DoCs) in relation to the custody of their children, and as such, it was important that they were reassured that where possible, the information they shared with me was confidential.

Research participants should not be identifiable in print or any other information made available to others (Morse, 1998; Punch, 1986). Essentially, research participants should not suffer any harm or embarrassment as a result of participating (Punch, 1986). The ethical issues surrounding confidentiality of information on illegal activities is, however, unclear (Bernard, 1988). The law is not specific under which circumstances the researcher would be required to report any incriminating information they discovered in the course of their research (Fitzgerald and Hamilton, 1996; Wright et al., 1998). The law is, however, a little more specific on the researcher’s obligations to report issues concerning the welfare of children. A requirement that the HRECs made was that the subject information sheet stated that the interview would be confidential so far as the law allows.

These legal issues made it particularly important to obtain informed consent from participants, ensuring that they were informed, that they are being researched in a particular manner, the nature of the research, and were aware of any potential repercussions of participating (Punch, 1986; Sirirassamee, 1993). This was done using an information sheet.

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25 All quotes and other information on participants presented in this thesis were checked for identifying information to ensure that they are not identifiable.
as required by the HRECs, which was provided to all participants. The legal jargon that is required in such consent forms is often confusing and frightening for many people (particularly marginalised people with lower levels of education, as was the case in this sample). In practice, much of the information sheet was paraphrased, and participants were encouraged to ask any questions they may have about the research. Each participant was given a copy of the information sheet to keep. Participants were given the option of using a pseudonym if it made them feel more comfortable. Some women did accept this offer.

Logistical issues with HRECs

Approval was initially sought and received from the Australian National University (ANU) HREC. Using additional recruitment strategies meant having to apply for approval to make such changes from this HREC. Additionally, the later sources of recruitment were based in health services, and as such required applications to several local health authority HRECs.

There were conflicting requirements within and across the different HRECs, despite approval already having been granted from the ANU HREC, for example, regarding the requirement of a consent form. Additionally, each HREC required different formatting and specific wording of the information and consent sheets for each of the different sources of recruitment. This was a problem to the point that negotiating with several HRECs at once became a barrier to the research. That each HREC met and worked to a different agenda made managing several committees concurrently very challenging.

This problem has been documented in Australia and overseas (Gilman, Anderton, Kosek, Garcia et al., 2002; Roberts, Bowyer, Homer and Brown, 2004; Walsh, Bowman and Dorward, 2001), particularly so in the drug and alcohol field where the possibility of legal
problems and issues of confidentiality are greater than among the general population. These difficulties delayed recruitment for approximately six months. Because of the problems with multiple HRECs, several potential sources of recruitment were not used, despite the full support of management and staff of such services.

Summary: Research design and methods

In this chapter, it has been demonstrated that the research design and methods employed were determined according to the aim and objectives of the research. The logistical and ethical issues associated with researching female injectors, especially in relation to their children, were given careful consideration in the research design and the tools selected.

Rigour was ensured throughout the research process using a range of strategies and tools. Again, the criteria by which the methods and findings of the research were assessed were determined according to the aims of the research.
Section 3: Findings

There are four chapters in this section in which the findings of the research are reported and discussed in relation to existing literature.

Chapter 7: Sample characteristics
Chapter 8: Women’s social experience of hepatitis C
Chapter 9: Hepatitis C and childbearing decisions
Chapter 10: The meaning of motherhood for women with hepatitis C

In chapters eight, nine and ten, quotes from the semi-structured interviews are used to demonstrate and exemplify the points being made. No real names or identifying information are provided with these quotes. Pseudonyms are used in order that the reader can contextualise each quote with other information about each individual participant, using other data provided throughout the thesis and the participant profiles in appendix 7.
Chapter 7: Sample Characteristics

This section outlines the demographic characteristics of the women who participated in the study. Although the study is qualitative in nature, and so statistical analysis is generally inappropriate (Morgan, 1993), the sample characteristics are presented in numerical terms in order to compare them with other samples, as well as to provide a description of their characteristics. Additionally, this chapter demonstrates the success of the maximum variation sample in obtaining a heterogeneous sample.

The demographic characteristics of the sample are summarised in Table 1. Each of the components of this table are summarised in this chapter, and where appropriate, compared to general Australian population samples, and the WLHC sample of women with hepatitis C (Gifford et al., 2003).
Table 1: Demographic characteristics of the sample

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Country of birth</th>
<th>Occupation+</th>
<th>Employment#</th>
<th>Income bracket (annual AUS)</th>
<th>Housing</th>
<th>Educational attainment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abby</td>
<td>24</td>
<td>Anglo</td>
<td>UK</td>
<td>None</td>
<td>No</td>
<td>$10,000 to $20,000</td>
<td>Rent</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Abigail</td>
<td>28</td>
<td>Anglo</td>
<td>Australia</td>
<td>Mother</td>
<td>No</td>
<td>Under $10,000</td>
<td>Rent</td>
<td>Year 11 to 12</td>
</tr>
<tr>
<td>Amy</td>
<td>34</td>
<td>Aboriginal/Anglo</td>
<td>Australia</td>
<td>Sex worker</td>
<td>No</td>
<td>Under $10,000</td>
<td>Rent</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Becky</td>
<td>26</td>
<td>Anglo</td>
<td>UK</td>
<td>Sex worker</td>
<td>No</td>
<td>$30,000 to $49,000</td>
<td>Rent</td>
<td>Year 11 to 12</td>
</tr>
<tr>
<td>Dawn</td>
<td>35</td>
<td>Anglo</td>
<td>Australia</td>
<td>Book binder</td>
<td>No</td>
<td>$10,000 to $20,000</td>
<td>Rent</td>
<td>Year 11 to 12</td>
</tr>
<tr>
<td>Ellie</td>
<td>29</td>
<td>Anglo</td>
<td>Australia</td>
<td>Painter/decorator</td>
<td>Yes</td>
<td>$30,000 to $49,000</td>
<td>Rent</td>
<td>Higher education</td>
</tr>
<tr>
<td>Emily</td>
<td>38</td>
<td>Anglo</td>
<td>Australia</td>
<td>Child care</td>
<td>No</td>
<td>$10,000 to $20,000</td>
<td>Rent</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Fiona</td>
<td>22</td>
<td>Anglo</td>
<td>Australia</td>
<td>Student (FT)</td>
<td>No</td>
<td>Under $10,000</td>
<td>Lodge</td>
<td>Year 11 to 12</td>
</tr>
<tr>
<td>Gemma</td>
<td>22</td>
<td>Anglo</td>
<td>Australia</td>
<td>Ex-sex worker</td>
<td>No</td>
<td>Under $10,000</td>
<td>Rent</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Georgia</td>
<td>39</td>
<td>Anglo</td>
<td>Australia</td>
<td>School teacher</td>
<td>Yes</td>
<td>$30,000 to $49,000</td>
<td>Rent</td>
<td>Higher education</td>
</tr>
<tr>
<td>Hannah</td>
<td>38</td>
<td>Anglo</td>
<td>Australia</td>
<td>Real estate agent</td>
<td>Yes</td>
<td>$30,000 to $49,000</td>
<td>Own home</td>
<td>Up to year 10</td>
</tr>
</tbody>
</table>

* Husband’s income
+ Reported as participant defined it, or as became apparent during the interview, except where details may be identifying.
# Excludes sex work
PT: Part time
FT: Full time
Table 1: Demographic characteristics of the sample continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Country of birth</th>
<th>Occupation*</th>
<th>Employment#</th>
<th>Income bracket (annual AU$)</th>
<th>Housing</th>
<th>Educational attainment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Janice</td>
<td>41</td>
<td>Aboriginal/Anglo</td>
<td>Australia</td>
<td>Social worker</td>
<td>Yes</td>
<td>$30,000 to $49,000</td>
<td>Rent</td>
<td>Higher education</td>
</tr>
<tr>
<td>Jean</td>
<td>45</td>
<td>Anglo</td>
<td>New Zealand</td>
<td>Student (PT)</td>
<td>No</td>
<td>Under $10,000</td>
<td>Rent</td>
<td>Year 11 to 12</td>
</tr>
<tr>
<td>Jessica</td>
<td>31</td>
<td>Anglo</td>
<td>UK</td>
<td>Care worker</td>
<td>Yes</td>
<td>$20,00 to $29,000</td>
<td>Rent</td>
<td>Higher education</td>
</tr>
<tr>
<td>Jocelyn</td>
<td>59</td>
<td>Anglo</td>
<td>Holland</td>
<td>Various blue collar</td>
<td>No</td>
<td>Under $10,000</td>
<td>Rent</td>
<td>Year 11 to 12</td>
</tr>
<tr>
<td>Julie</td>
<td>32</td>
<td>Anglo</td>
<td>New Zealand</td>
<td>Student (FT)</td>
<td>No</td>
<td>$10,000 to $20,000</td>
<td>Rent</td>
<td>Year 11 to 12</td>
</tr>
<tr>
<td>Justine</td>
<td>36</td>
<td>Anglo</td>
<td>Australia</td>
<td>Ex-sex worker</td>
<td>No</td>
<td>Under $10,000</td>
<td>Rent</td>
<td>Year 11 to 12</td>
</tr>
<tr>
<td>Karen</td>
<td>43</td>
<td>Anglo</td>
<td>Australia</td>
<td>Housewife</td>
<td>No</td>
<td>$20,00 to $29,000</td>
<td>Own home</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Kate</td>
<td>38</td>
<td>Anglo</td>
<td>Australia</td>
<td>Accountant</td>
<td>No</td>
<td>$70,000 to $99,000*</td>
<td>Own home</td>
<td>Higher education</td>
</tr>
<tr>
<td>Kath</td>
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<td>Anglo</td>
<td>Australia</td>
<td>Home maker</td>
<td>No</td>
<td>$10,000 to $20,000</td>
<td>Rent</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Kelly</td>
<td>27</td>
<td>Anglo</td>
<td>UK</td>
<td>Mother</td>
<td>No</td>
<td>$10,000 to $20,000</td>
<td>Rent</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Kylie</td>
<td>35</td>
<td>Anglo</td>
<td>New Zealand</td>
<td>Housewife</td>
<td>No</td>
<td>Under $10,000</td>
<td>Rent</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Linda</td>
<td>31</td>
<td>Anglo</td>
<td>USA</td>
<td>Mother</td>
<td>No</td>
<td>$10,000 to $20,000</td>
<td>Rent</td>
<td>Year 11 to 12</td>
</tr>
<tr>
<td>Lindsay</td>
<td>27</td>
<td>Anglo</td>
<td>New Zealand</td>
<td>Student (PT)</td>
<td>Yes</td>
<td>Under $10,000</td>
<td>Rent</td>
<td>Up to year 10</td>
</tr>
</tbody>
</table>

* Husband’s income
+ Reported as participant defined it, or as became apparent during the interview, except where details may be identifying.
# Excludes sex work
PT: Part time
FT: Full time
Table 1: Demographic characteristics of the sample continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Country of birth</th>
<th>Occupation+</th>
<th>Employment#</th>
<th>Income bracket (annual AUS)</th>
<th>Housing</th>
<th>Educational attainment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Naomi</td>
<td>38</td>
<td>Anglo</td>
<td>UK</td>
<td>None</td>
<td>No</td>
<td>Under $10,000</td>
<td>Rent</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Rebecca</td>
<td>37</td>
<td>Anglo</td>
<td>Australia</td>
<td>Sex worker</td>
<td>No</td>
<td>Under $10,000</td>
<td>Motel room</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Sally</td>
<td>38</td>
<td>Anglo</td>
<td>Australia</td>
<td>Social worker</td>
<td>Yes</td>
<td>$30,000 to $49,000</td>
<td>Rent</td>
<td>Higher education</td>
</tr>
<tr>
<td>Sarah</td>
<td>45</td>
<td>Anglo</td>
<td>Australia</td>
<td>IT Project manager</td>
<td>No</td>
<td>$30,000 to $49,000</td>
<td>Own home</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Sharon</td>
<td>35</td>
<td>Anglo</td>
<td>Australia</td>
<td>Sex worker</td>
<td>No</td>
<td>$10,000 to $20,000</td>
<td>Rent</td>
<td>Year 11 to 12</td>
</tr>
<tr>
<td>Sophie</td>
<td>27</td>
<td>Anglo</td>
<td>Australia</td>
<td>Welfare worker</td>
<td>Yes</td>
<td>$30,000 to $49,000</td>
<td>Parental</td>
<td>Higher education</td>
</tr>
<tr>
<td>Tammy</td>
<td>47</td>
<td>Anglo</td>
<td>New Zealand</td>
<td>Receptionist</td>
<td>Yes</td>
<td>$30,000 to $49,000</td>
<td>Rent</td>
<td>Year 11 to 12</td>
</tr>
<tr>
<td>Theresa</td>
<td>42</td>
<td>Anglo</td>
<td>Australia</td>
<td>Political administrator</td>
<td>Yes</td>
<td>$30,000 to $49,000</td>
<td>Rent</td>
<td>Higher education</td>
</tr>
<tr>
<td>Valerie</td>
<td>39</td>
<td>Anglo</td>
<td>Australia</td>
<td>Ex-sex worker</td>
<td>No</td>
<td>Under $10,000</td>
<td>Lodge</td>
<td>Up to year 10</td>
</tr>
<tr>
<td>Veronica</td>
<td>38</td>
<td>Anglo</td>
<td>Morocco</td>
<td>Ex-sex worker/receptionist</td>
<td>No</td>
<td>$10,000 to $20,000</td>
<td>Rent</td>
<td>Up to year 10</td>
</tr>
</tbody>
</table>

* Husband’s income
+ Reported as participant defined it, or as became apparent during the interview, except where details may be identifying.
# Excludes sex work
PT: Part time
FT: Full time
Age

The majority of the sample was in their late 20s to late 30s. The age range distribution is shown in Table 2 below. The average age of women in the sample was 35 years, exactly the same as in the WLHC sample (Gifford et al., 2003). The women’s ages ranged from 22 to 59. The age range in this sample was more restricted than in the WLHC sample (Gifford et al., 2003) in order to target women in their childbearing years. A wide age range of women with hepatitis C was used to cover a broad spectrum of women’s childbearing careers, in line with the maximum variation sampling strategy described in chapter six. The importance of motherhood and what it entails may vary according to age, and using a wide age range helps to capture these differences.

In 1999 the most common age group within which Australian women had their first child was 25-29 years (35 per cent); 31 per cent between the ages 15-24; and about 24 per cent between ages 30-34 years and almost 10 per cent aged 35 and above (Australian Bureau of Statistics, 2002b). Given the age distribution of the present sample, compared with current Australian norms, the majority of the sample would be likely to have at least considered childbearing recently. This sample is slightly older than the profile of most women currently having children. This may be advantageous to the research question because they are more likely to have recently considered childbearing or to have had experience of childbearing. Having an older sample is also more likely to include women who have made final decisions to remain childless and provide reasoning behind their decisions, which may or may not be related to hepatitis C.
Table 2: Age distribution of sample

<table>
<thead>
<tr>
<th>Age range*</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>15-24</td>
<td>3</td>
</tr>
<tr>
<td>25-29</td>
<td>7</td>
</tr>
<tr>
<td>30-34</td>
<td>4</td>
</tr>
<tr>
<td>35-39</td>
<td>13</td>
</tr>
<tr>
<td>&gt;40</td>
<td>7</td>
</tr>
</tbody>
</table>

* These age ranges were used in order to compare the age distribution of this sample with Australian population norms (Australian Bureau of Statistics, 2002b).

Ethnicity

Almost the entire sample was of Anglo ethnicity, with the exception of two women who described themselves as being of mixed race. Both of these women were part Indigenous Australian and part Anglo-Australian. Only one woman reported that English was her second language.

Country of birth

The majority (62 per cent) of this sample was Australian born. Five women were born in the UK, and another five in New Zealand. One woman was from The Netherlands, another from Northern Africa and another was born in the USA. With the exception of two of the women who were born in England, those women who were born outside of Australia had spent most of their adult lives in Australia. This sample includes a greater proportion of non-Australian born women than the WLHC sample (Gifford et al., 2003), in which 86 per cent were born in Australia.
Occupation

A large proportion of the sample reported their occupation to be homemaker (wife/mother). Eight women had professional or semi-professional occupations, which were mostly in or relating to, social work. Four women reported currently being engaged in sex work and another four were former-sex workers (of whom one occupied a semi-professional occupation at the time of interview). About four women were usually employed in various blue-collar occupations, although were not all working at the time of interview. Several women reported having no occupation. This range of occupations is reflected in their relative incomes.

Employment

Eight women (24 per cent) reported being employed full time, and two women (six per cent) reported being employed part-time. These employment levels were lower than among the Australian female population. In 1996 33.5 per cent of Australian women reported being employed full time and another 25.5 per cent being employed part time (Australian Bureau of Statistics, 2002c).

Income

The majority of the sample reported low gross individual income levels. The income levels of the sample are summarised in Table 3. Twenty-one (62 per cent) women earned under $19,000 a year before tax. The Australian national average weekly personal income for women is $365 (almost $19,000 annually), and so the majority of these women had incomes lower than the general population average. Of these 21 women, 12 women (57 per
cent) reported an income less than $10,000 a year, approximately half the national average income for women in 1999-2000, (Australian Bureau of Statistics, 2002b). Women in these lower income brackets generally reported being dependent on state pensions and benefits.

Ten women reported earning between $30,000 and $49,000 a year, which is roughly average, based on Australian female wage norms (Australian Bureau of Statistics, 2003b). None of the women had a very high income compared to the general population.

One woman reported the income of her partner as at the time of interview she was not earning anything because she was not in paid employment as she was caring for her children full time. This woman reported to have the highest income, but this was her combined household income, rather than her individual income as reported by the other women.

Table 3: Income distribution of sample

<table>
<thead>
<tr>
<th>Income range</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>$1 - $9,999</td>
<td>12</td>
</tr>
<tr>
<td>$10,000 - $19,000</td>
<td>9</td>
</tr>
<tr>
<td>$20,000 - $29,000</td>
<td>2</td>
</tr>
<tr>
<td>$30,000 - $49,000</td>
<td>10</td>
</tr>
<tr>
<td>$50,000 - $69,999</td>
<td>0</td>
</tr>
<tr>
<td>$70,000 - $99,999</td>
<td>1</td>
</tr>
</tbody>
</table>
Housing

Most women reported renting their home at the time of interview and of these, at least 14 were in public housing. Only four women reported owning their home. Four women reported living in their parental home, all with their mother. One woman reported living in a motel room, and that she was essentially homeless.

Home ownership is often used as an indicator of financial wealth and stability (Australian Bureau of Statistics, 2004). In Australia, the majority of households own their own home (Australian Bureau of Statistics, 2002a), although this does vary according to age. Very few women owned their homes and this can be taken as an indicator of their overall low SES.

Education levels

Twenty four women (70 per cent) reported having only school-level education (see Table 4). Fifteen women reported having completed education up to year 10. Nine women had completed year 11 or year 12 (senior school). Two women had completed a TAFE course and eight had tertiary level (university) education.

These educational characteristics are almost identical to those in the WLHC sample, in which 65 per cent had completed up to year 11 but not year 12 (Gifford et al., 2003), though are not representative of Australian norms. In the general population, 31 per cent of people aged 15 to 64 years are educated up to year 10, compared with 44 per cent in this sample (Australian Bureau of Statistics, 2002d). There was also a smaller proportion of the sample who had completed year 12 (21 per cent) than the Australian population (42 per cent) (Australian Bureau of Statistics, 2002d).
However, a greater proportion of this sample reported having completed university level education: 24 per cent compared to the national figure of 17 per cent (Australian Bureau of Statistics, 2002d).

**Table 4: Educational attainment**

<table>
<thead>
<tr>
<th>Level of education</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Up to year 10</td>
<td>15</td>
</tr>
<tr>
<td>Year 11 or 12</td>
<td>9</td>
</tr>
<tr>
<td>TAFE qualification</td>
<td>2</td>
</tr>
<tr>
<td>Tertiary qualification</td>
<td>8</td>
</tr>
</tbody>
</table>

**Suburb of residence**

The suburbs in which the women lived were categorised into 10 districts. A summary table of these categories is provided in appendix 1. Twenty-four (70 per cent) of the women lived in suburbs close to Central Sydney. Seven women lived in outer-Sydney suburbs. Three women lived in areas a long distance from inner city Sydney.
Injecting drug use

The majority of the sample (91 per cent) reported being current or past injectors, a greater proportion than the 83 per cent in the WLHC sample (Gifford et al., 2003). Only three women (9 per cent) reported never injecting illicit drugs (see Table 5). The level of IDU reported by the women was highly variable, and for each of the women, varied over time. Some women reported highly dependent and frequent injecting behaviour, whilst others reported only occasional use.

Table 5: Injecting drug use

<table>
<thead>
<tr>
<th>IDU</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current</td>
<td>24</td>
</tr>
<tr>
<td>Past</td>
<td>7</td>
</tr>
<tr>
<td>Never</td>
<td>3</td>
</tr>
</tbody>
</table>

Current injectors

Twenty-four (71 per cent) of the women interviewed were current injectors at the time of interview, compared with 47 per cent in the WLHC sample (Gifford et al., 2003). Current IDU was defined as having injected in the last 12 months.

Past injectors

Seven women (21 per cent) were past injectors, compared to 36 per cent in the WLHC sample (Gifford et al., 2003). The time since last injection ranged from 12 months to 25 years. Of these women, three had stopped injecting in the preceding six months, once they discovered they were pregnant.

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26 Time since last injection is detailed in the IDU and methadone programme enrolment table in appendix 3.
**Methadone maintenance treatment**

The women were not asked if they were on methadone maintenance treatment in the questionnaire, but this issue often came up during the interview. Nineteen of the women interviewed reported being on a methadone program at the time of interview. At least two other women had been on a methadone programme prior to the interview. Nine women (about a quarter of the sample) reported not currently being on methadone but it was unclear whether or not some of these women had been on methadone previously.

**Partner**

The women were not asked whether or not they had a partner in the questionnaire, but this was explored in all of the semi-structured interviews. Nineteen women reported having a partner at the time of interview, of whom 17 were living with their partner. Two women reported that they were lesbian, but only one of these women was in a relationship at the time of interview, and she reported to be living with her female partner.

Two women reported having physically abusive partners at the time of interview. They were not directly asked for this information, so it may be the case that more of these women were in abusive relationships. Three women reported being in past long term relationships with men who were abusive.
**Existing children**

The women were asked in the interview, not in the questionnaire, about how many, if any, children they had at the time of interview. Twenty-two women (65 per cent) had children, although one woman reported her child being taken from her at birth when she was a teenager. Twelve women had not had any children. Seven women had children who were not in their custody.

Ten women who had children knew they had hepatitis C before their pregnancy. Three women were diagnosed with hepatitis C when pregnant. Five women were pregnant at the time of interview, and of these four already had children. Thirteen women reported living with their dependent children, and two reported that although their children live with them, because of children’s ages, they were no longer dependent. The major reason for the large discrepancy between the number of women who had children (22) and those who reported living with dependent children (13), was because their children were in the custody of other people.

There was a slightly larger proportion of women in this sample (38 per cent) living with dependent children than the 34 per cent reported in the WLHC sample (Gifford et al., 2003).
Source of hepatitis C infection

Many women expressed varying levels of doubt about the exact source of their infection, whilst others were able to identify the source and many other details, such as the time and place when they acquired hepatitis C. Some women were able to report the source of infection and the period of time in which they became infected because of regular hepatitis C, and other viral testing. Table 6 summarises the sources of infection for the women in this sample.

Table 6: Source of hepatitis C infection

<table>
<thead>
<tr>
<th>Source of hepatitis C infection</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>IDU</td>
<td>25</td>
</tr>
<tr>
<td>Medical</td>
<td>2</td>
</tr>
<tr>
<td>Piercing</td>
<td>1</td>
</tr>
<tr>
<td>On purpose</td>
<td>1</td>
</tr>
<tr>
<td>Don’t know</td>
<td>5</td>
</tr>
</tbody>
</table>

IDU

Twenty-five of the 34 women (74 per cent) reported that the source of their hepatitis C infection was most probably IDU. Of these, one woman reported that it was either through IDU or a tattoo. An estimated 80 per cent of Australian hepatitis C infections are believed to have been through IDU (Dore et al., 2003). As such, the source of hepatitis C infection in this sample is similar to most Australian hepatitis C infections.

Medical procedures

Two women reported that their hepatitis C infection was through a medical procedure, one of which was in Australia in the 1980s and the other was in Asia.
Unknown source

Five women reported that they did not know how they contracted hepatitis C. Of these, three were current or past injectors.

Other sources

One woman reported contracting hepatitis C through a piercing in Asia. Another woman reported that she infected herself on purpose as a demonstration of her love for another woman. She did this by pricking herself with a needle that her partner had used, knowing that her partner had hepatitis C.

Duration of infection and time since diagnosis

The women were not asked about the duration of their hepatitis C infection or the date when they were diagnosed with hepatitis C in the questionnaire, but they were asked questions about this in the semi-structured interviews. Some women only reported their estimation of when they think they became infected with hepatitis C, whilst others only reported the approximate date on which they were diagnosed with hepatitis C. Some women discussed both the duration of infection and time since diagnosis. These estimations are summarised in Table 7.

Table 7: Estimated duration of hepatitis C infection

<table>
<thead>
<tr>
<th>Estimated duration of infection</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 year and under</td>
<td>2</td>
</tr>
<tr>
<td>2-5 years</td>
<td>11</td>
</tr>
<tr>
<td>6-10 years</td>
<td>7</td>
</tr>
<tr>
<td>11-20 years</td>
<td>10</td>
</tr>
<tr>
<td>Over 20 years</td>
<td>4</td>
</tr>
</tbody>
</table>
Overall, the average duration of infection, based on their estimates, was just under 10 years, ranging from less than 12 months to 30 years. The average time since diagnosis was just over seven years. Only two women reported having had hepatitis C for under one year; one women for between one and five years; seven women between five and 10 years; 10 women for between 10 and 20 years and four women estimated that they had been living with hepatitis C for more than 20 years. Estimates of the duration of infection are based upon risk factors, such as IDU and medical procedures, and the dates of tests for hepatitis C.

Sample overview

The parameters of the hepatitis C epidemic have not been clearly defined, are based on estimates and are thwarted with inherent reporting caveats. Consequently, the characteristics of all women with hepatitis C in Australia are not known and so it is therefore necessary to rely on population based large surveys such as WLHC sample (Gifford et al., 2003) for indications of these characteristics, while recognising the bias that has possibly been introduced through recruitment methods and related issues. Other sources of information on the characteristics of women living with hepatitis C are epidemiological studies, but these too have problems, largely because they have been conducted in specific subpopulations, none of which are representative.

Overall, this sample is similar to that in a large sample of women with hepatitis C in Australia (Gifford et al., 2003), based on their injector status, and indicators of SES, such as education levels and employment status. Also, the sample in this study is similar to samples of injectors and samples of people with on hepatitis C, such as ‘Estimates and Projections of the Hepatitis C Virus Epidemic in Australia’ (ANCAHRD, 2002).
Given that the sample appears to be similar to other samples of women with hepatitis C, and there are a broad range of women with hepatitis C included in the sample, it is expected that the issues raised by them are salient for this group, even if not all of high prevalence. The larger-scale issues identified in this study are likely to be of relevance to many women with hepatitis C. It does not mean, however, that all of the issues highlighted in the study are of relevance to all women with hepatitis C.
Chapter 8: Women’s Social Experiences of Living with Hepatitis C

The interview data indicate there are many different experiences of living with hepatitis C. There were some common themes and patterns in this heterogeneous sample of women with hepatitis C. This chapter will investigate these experiences of living with hepatitis C and examine the key social issues that arose in the interviews, including: diagnosis and prognosis; monitoring hepatitis C related health; social stigma and resultant discrimination; hepatitis C related health care; hepatitis C symptoms; lifestyle changes; disclosure of hepatitis C; impact of hepatitis C upon social relationships; and changed self-perception.

Stigma and discrimination

All of the women interviewed reported experiencing social stigma in some way because of their hepatitis C, and that they suffered negative effects of stigmatisation. This social stigma is woven through all of their social experiences of living with hepatitis C. The vast majority of the sample reported this to be the most problematic issue they faced in living with hepatitis C. Most women described hepatitis C as a social label, which is highly discrediting, in line with the stigma described by Goffman (1963). Most of this stigma was reported to be related to the IDU associated with hepatitis C. The infectiousness of the hepatitis C virus and the sickness that it can cause also contributed to this stigma. These different components of hepatitis C stigma: association with IDU and having an infectious disease, are mutually reinforcing. O’Brien et al (2001) reported that women living with hepatitis C who were current injectors were more likely to fare worse on several indicators of wellbeing, including being more likely to be discriminated against.
I’ve been looked down on by medical people a couple of times, not so much for having hep C but because I use drugs. I would think it’s because I’m a junkie, not because I’ve got something. *Dawn*

People go, ‘where did you get it from?’ And then if you get it from there [IDU] it’s a social stigma to have been a user of any type [drug user]. I can understand why people don’t like me. *Fiona*

Karen, as a never-injector reported that she feels she is stigmatised because she has hepatitis C but for a different reason. She believed that as a new disease, about which little is known and the treatments for which are very limited, people are overly fearful and this results in stigma and discrimination, as has been the case for other diseases in the past, (Hardey, 1998; Mack, 1991; Nelkin and Gilman, 1991).

Well it’s like diabetes, you know, because years ago a diabetic was treated like someone with HIV … well people used to just drop dead. There wasn’t insulin in those days. They didn’t really know what to do. This [hepatitis C] is only a new thing. *Karen*

When certain behaviours are associated with particular diseases, the social meanings given to the disease are shaped by social attitudes to the behaviours with which they are associated. Individuals living with such diseases are blamed, or not blamed for their condition depending on whether or not they acquired it through stigmatised behaviours or not. This subsequently influences the way that they are treated – if they are to blame then they are often shunned by society. If, however, they are seen to not be responsible for their condition then they are treated with sympathy and compassion (Brandt, 1991; Kateb, 1991; Mack, 1991; Nelkin and Gilman, 1991; Quinton, 1991; Rosenberg, 1991).
Hepatitis C was reported here to be an indicator of IDU, and vice versa. Women identified as injectors are often assumed to have hepatitis C, as Janice demonstrates when she was in hospital having her second child.

But at that stage, as I said, hadn’t been diagnosed as having hep C. But the interesting thing was that they all assumed that I was because I was an ID [injecting drug] user, they all assumed that I was hep C positive. You know, they were always quite surprised if there was a new nurse coming on duty, they would look at your charts, ‘oh you don’t have hep C, there must be a mistake,’ you know. And they were always shocked that I didn’t have it because I was a user. Janice

**Auxiliary traits**

Hepatitis C is related to IDU, and everything that is associated with the injectors’ social identity. The interview data indicates that the stereotypical injector is desperate, self-centred, highly immoral, untrustworthy, criminal, dirty, diseased, polluted and lacking self-control. Having hepatitis C adds a further dimension to the ‘junkie’ stereotype − of being diseased. Disclosing one has hepatitis C means that others will often assume them to also possess these auxiliary traits, and unfortunately, the data indicates that it is often a case of guilty until proven innocent.

I suppose people fear [hepatitis C] because it’s associated with drug addicts and stuff. And there is a big fear of that. You know, because it’s a very scary strange thing, some people die and people get hurt because they know loved ones that have died. I suppose they are scared of that scene and people don’t want to be a part of it. And they don’t want to have to deal with it, which is fine, there’s nothing wrong with that. But also, maybe they’re saying ‘she’s got hep C, what is she doing, has she got any other disease too? She might have something else. She might have just come up here and infected us.’ Does that mean she’s going to go out and … because she’s got hep C, she might be really cautious about how she does stuff. You know, she might be really, you know, not caring kind of like really skanky, or you know really unclean and stuff. So what else is she going to bring home? What other diseases could she have?’ There is that, as well a real fear. Fiona
Stigma associated with hepatitis C is worse for women than men

Some women reported that they feel as women, they are more highly stigmatised than men living with the virus, who have contracted it through similar means. Kath reported that it is generally perceived to be more deviant for a woman to have hepatitis C than for a man. However, this is not exclusive to hepatitis C, and Kath compared it to the way in which it is less acceptable for women to have sexually transmitted infections than for men.

For women [with hepatitis C], other people find them more unattractive. Like men get away with it because they can [do] whatever and women have to look after themselves. [Q: What is it about being female that people see it as being so much worse?] I don’t know, it’s just from being female, you’ve got that … It’s like having herpes or something. A man can get away with it, say they don’t have it, like what happened to me [when she acquired hepatitis C through sharing injecting equipment with her partner who told her he did not have hepatitis C.] Kath

The stigma associated with hepatitis C, like other forms of deviance, has been reported to be worse for women than for men (Day et al., 2004; Day et al., 2003), probably because of women’s social roles (Temple-Smith et al., 2003). Zickmund et al (2003) reported that stigmatisation was a prevalent problem among people living with chronic hepatitis C in a clinical sample from a hospital in the USA. They too found that women were more likely than men to report stigmatisation, as did other studies. They attribute this to the infectious nature of hepatitis C and the way in which this clashes with the image of women as carers of infants, in line with the findings of Temple-Smith et al (2003). However, they did not find that levels of stigmatisation varied according to mode of hepatitis C acquisition, as we might expect based upon the reports in this study, which indicate that most stigmatisation is related to the close association of the virus with IDU.
The deviance that is associated with IDU is perceived to be greater for women, and as such is less acceptable (Broom, 1994; Copeland, 1994; Sargent, 1992; Swift and Copeland, 1999). In particular, these traits are at odds with the characteristics expected of mothers. Women with hepatitis C fail as women because in becoming ‘diseased’ they have failed in their feminine social roles, as carers of children, as Lawless et al (1996) found for women with HIV.

**Notions of pollution**

The women in this study reported their identity to have been ‘polluted’ by hepatitis C. In having hepatitis C, women are perceived to be polluted biologically, because they have acquired a virus. However, this pollution is also symbolic, in that it represents social disease, because of the deviant behaviour associated with the transmission of the virus. Several women reported that people treated them and made them feel as though they were the virus, rather than *having* it. According to Link and Phelan (2001), this is because of the process of stigmatisation, in which the stigmatised individual becomes the ‘thing’ they are labelled.

> It really makes you start to feel like you are the disease, you know instead of, you have got the disease, you are the disease. And there is a difference there. *Fiona*

This notion of pollution was internalised by some women who described feeling ‘infectious’, ‘toxic’, and ‘polluted’, especially in relation to children. When explaining to her children why they cannot touch their mother’s blood when she cuts herself, Kelly tells them ‘Mum’s blood is toxic.’

Sally claimed that all forms of viral hepatitis have some sort of pollution associated with them, but each of differing nature. Because hepatitis C is associated with IDU, it is less
acceptable to have hepatitis C, rather than the other forms of hepatitis that are contracted through other routes, such as polluted water (hepatitis A) or unprotected sexual contact (hepatitis B). There is, however, some stigma associated with the ways in which these other forms of hepatitis are acquired.

People aren’t as worried about saying they have got hep A or something, even though it might be, you haven’t washed your hands or done something. I don’t know, certain things are not as bad as other things. Although all hepatitises have that sort of dirty thing about them. Sally

The interview data indicate that among those women who had never injected, there was a physical element of pollution, although because of association with injectors, there was an additional element of pollution that might not be the case if the virus were not associated with a stigmatised organisation.

These notions of pollution are not exclusive to hepatitis C, but do appear to be worse for people with hepatitis C, rather than other forms of viral hepatitis. Jessica claims that this is because hepatitis C is so closely associated with IDU, which implies moral pollution as well as viral infection.

No matter how people try to be about viruses they still have this thing, like you are unclean because you have a virus. Whether it be HIV, hepatitis C, HBV, it’s still, you know because people have these attitudes, because it can never happen to them, especially something like hepatitis C because it relates to injecting drug use. Jessica
Consequences of stigmatisation

Stigmatisation identifies people as different, making it possible to exclude them from normal society as they represent dangerous ‘others’. The stigma associated with hepatitis C means that people living with the virus are identified as deviants and as such represent a risk, both of viral infection and moral pollution. People living with hepatitis C are thus excluded from normal social roles and activities, such as employment (Platt and Gifford, 2003). The women in this study reported being excluded from several different realms of social life, including the family, employment, and for some women, motherhood. There were reports of being rejected and discriminated against by both medical professionals and personal friends and family because of the stigma associated with hepatitis C. Every woman reported fearing social rejection because they have hepatitis C, largely because of its association with IDU. This corresponds with the findings of Temple-Smith et al (2003) that women tend to report fearing rejection because they have hepatitis C, but men are not so concerned about this. This fear prevented some women from accessing the care and support that they needed, and was the source of a great deal of anxiety.

Discrimination is a consequence of stigmatisation. Hepatitis C related discrimination in Australia has been highlighted in several publications (Anti-Discrimination Board of New South Wales, 2001; Day et al., 2003; Puplick, 2001). It has been shown that most hepatitis C related discrimination occurs in health care settings, probably because disclosure is most likely to occur in a medical setting (Anti-Discrimination Board of New South Wales, 2001). Hepatitis C related discrimination also occurs in social settings such as among family and friends (Day et al., 2004; Day et al., 2003) and work (Platt and Gifford, 2003). In social settings, women with hepatitis C may not receive the same degree of discrimination.
because these others (friends and family) have a greater knowledge about their actual social identity (Goffman, 1963), as opposed to medical professionals who have to make assumptions about her social identity based upon the limited information they have at the time of contact with them. The interview data contains many examples of hepatitis C related discrimination in health care settings and for this to usually be related to the IDU with which the virus is associated. Several women reported occasions on which they stood up to the medical professionals who they perceived to have treated them badly. This demonstrates that while they might not be socially powerful, they do not necessarily lack agency.

Even doctors down here [Sydney] have stereotypes, and as soon as I told one of my doctors, his view of me changed. He got very abrupt with me. And I actually stood up and told him what I thought and went off. But then he actually became a good doctor after that, because I yelled at him, I said ‘how dare you?’ You know? He hasn’t got the right to do that. *Abby*

How would they [medical professionals] feel if they were treated like they treat hep C people? I said that to one nurse and she goes, ‘well I’d treat you a lot better if you were a better class of person and if you had never used drugs, drugs are illegal. Did you know that can you read?’ And I said, excuse me, but I did not get it [hepatitis C] through drug use and I can tell you now, you could sue my arse off if I treated you like this and all I ask is that you just do your job. And she quietened down after that because in a round about way I said I would sue. She would sue me if I treated her the same way. *Lindsay*

There were also some reports of discrimination based upon the infectiousness of the virus. It is possible that the perceived risk of infection was influenced by the association with IDU, as all risks are socially constructed and defined by social acceptability (Caplan, 2000; Day, 2000; Douglas, 1985; Douglas, 1994; Foege, 1991; Gifford, 1986; Glick Schiller, Crystal and Lewellen, 1994; Lupton, 1993; Lupton, 1995; Lupton, 1999; Petersen and Lupton, 1996; Southgate, Day, Kimber, Weatherall et al., 2003; Zule, 1992).
After a friend rejected Fiona’s idea to live together because she perceived there to be a risk of household transmission of hepatitis C, Fiona feared that she would be asked to leave her current share house if she disclosed her hepatitis C to her current housemates because of their perceived risk of infection and a changed view of her character. In disclosing her hepatitis C, she would also reveal that she was an injector, and as such this would drastically change their perception of her social identity, and her character traits.

I know I wouldn’t probably be allowed to live there if I had it. I feel like that would be like, well, then they would go, ‘oh she’s is obviously a drug user then and we don’t want drug users,’ and dah dah dah dah, which is really gets to me because if they didn’t know this, they are quite happy with who I am you know. Fiona

Women of higher SES in this sample appeared to be more able to defend their legitimate social status than women of lower SES. This is what we might expect, given that ‘for stigmatisation to occur, power must be exercised’ (Link and Phelan, 2001: p363; Schur, 1971). Women such as Theresa, and Sarah were past injectors, but also middle class, professional women who were able to articulate their needs and discuss their options with their doctors, sharing the same language. Despite being past injectors, they reported that they had not felt that they had been discriminated against severely. They did, however, feel stigmatised, which restricted who they disclosed their hepatitis C status to in order to minimise the effects of stigmatisation. It may be the case that while they were able to defend themselves from discrimination, they were unable to avoid the social stigma associated with the virus.

Other women, particularly poor, street-based women who are current or past injectors, however, reported feeling discriminated against and frustrated with their medical care. They felt their hepatitis C was not explained to them properly and so they were unable to make
the right demands of their doctors. An injector of higher SES, for example, someone with a professional occupation, would be more likely to get what they need from the medical profession and not be stereotyped. People of lower SES, however, were less likely to get what they need by legitimate means and end up falling deeper into deviance. The further deviance that ensues as a result of being labelled as a deviant is commonly referred to as secondary deviance, based upon labelling theory introduced by Becker (1963).

If you go in there [doctor’s surgery] looking like a professional or something like that and you are asking, ‘I can’t sleep and I need this and that’, you get it. If you go in there looking like a drug user, [they] immediately think that you are, or you say you are, a drug user. So what happens? You go away and you score [buy illicit drugs] instead. People do that because doctors just assume straight away. Sally

People of higher SES are more able to defend themselves from these assumptions of their character because their other traits, which permit them to hold a higher social position, are in conflict with those of the stereotypical ‘junkie’ (Pfuhl and Henry, 1993). Others of lower SES, however, are more likely to be assumed to possess these negative characteristics and as such are judged and rejected, leading to further social marginalisation. However, most samples of injectors are of lower SES (Day, Ross, White and Dolan, 2002a; Loxley et al., 1995). The interview data indicates that the stereotype of the ‘junkie’ remains strong in the minds of much of the general population and this presents significant problems for women living with hepatitis C.

At the time of interview, Jocelyn’s physical hepatitis C symptoms exceeded the social impact of living with the virus but she was passionate in her explanation of the way in which the social stigma associated with the virus served to worsen the physical problems she experienced. She reported that the stigmatised nature of hepatitis C restricts the
amount of formal and non-formal support she had available to her, to help her cope when she is sick. Jocelyn highlighted that supports available to people living with HIV/AIDS exist because among people living with HIV/AIDS in Australia, mainly gay men, there is a strong sense of community. This community affords people within it greater social status and greater power. Injectors who make up most of the population of people with hepatitis C do not have such a well-developed sense of community. Many injectors are poor and socially marginalised, with little resources to direct to supporting people living with hepatitis C, nor to put political pressure on others to do so.

Many women reported avoiding health care because of the discrimination and judgement they face, which concurs with The Anti-Discrimination Board of New South Wales (2001) report on hepatitis C related discrimination. In avoiding health care because of discrimination, women with hepatitis C are effectively denied access to care that they need, and their health and wellbeing may deteriorate as a result. Within contemporary society, individuals are expected to consult a medical professional about health problems. When they do not do so, they are perceived to be to blame for their malaise and problems that this may present to society in terms of infection risk and being an unproductive member of society, particularly if it renders them unfit to work and means they claim state benefits. When unable to fulfil their normal social roles they become deviant in the way that Parsons (1951) describes sickness as deviance. People with hepatitis C are often held to blame for their condition, and so they are more likely to be punished than cared for, as they do not fulfil one of the four central tenets of the sick role concept as defined by Parsons; that the sick person is not blamed for their condition.

The benefits that are expected from seeking help with hepatitis C, like drug dependence, must be weighted against the problems that seeking help is likely to present. Several women
reported that they avoid health care because of this, indicating the severity of the implications of this social labelling.

Real and perceived discrimination

Many women in the sample reported having experienced hepatitis C related discrimination. Discrimination can, however, be both real and perceived (Goffman, 1963; Link and Phelan, 2001). In either case it can have serious detrimental effects upon an individual. Sometimes it is not evident whether or not an individual is treated unfavourably at all, or for what reason. It is possible for those with a social stigma, such as women with hepatitis C, to perceive that they are being discriminated against, whether or not it actually occurs. In dealing with a great deal of discrimination on a regular basis, and over an extended period of time, as many injectors do, it is possible that they are more likely to assume discrimination. Conversely, people who have always been discriminated against may be unable to detect discrimination as they are unaccustomed to being treated more favourably.

Some women acknowledged that some discrimination may be perceived rather than actual, but that it is often impossible to distinguish whether that is the case or not.

It depends on how you interpret that. She [medical receptionist or practitioner] might be just a bitch, or be having an off day and not wanting to do anything. Or she might resent you because you’re on methadone. *Dawn*
Being treated like a leper

Several women reported being treated ‘like a leper’, that is, people did not want to be close to them for fear of contagion, and a fear of not wanting to be around someone who is sick. By distancing themselves from ‘diseased’ people they are out of sight and out of mind and do not present a risk to them. Hardey (1998) describes the way in which diseases such as cholera and typhoid have represented a ‘fearful other’ as they posed a threat to societies. Some diseases are associated with ‘others’; other races, other cultures and other behaviours (Hardey, 1998). In creating this ‘otherness’, boundaries are created and those groups associated with these diseases are distanced and thus represent less of a threat (Nelkin and Gilman, 1991). This has serious negative consequences for those identified as ‘others’.

Emily reported being treated like a leper because she had hepatitis C when she gave birth to her son 10 years ago.

It was a dreadful experience in the hospital, being treated like a leper. Emily

Kate also reported being treated in a similar way when she had her second baby in hospital more recently.

They were really, oh, as if I was a leper or something. Kate

Georgia reported that generally she was not usually treated as a ‘sick’ person, but instead as a leper, indicating that to be a leper means more than being ill and contagious. There is a social and moral component to having such a stigmatised disease. It is possible that these
women were treated in this way because of the symbolic nature of their disease, women with hepatitis C are socially, as well as virally polluted.

Not as a sick person but sometimes they do treat you as a bit of a sort of leper. Depending on their level of ignorance really. *Georgia*

**Wrongly applied deviant labels**

There were three women in this sample who had never injected illicit drugs, although some of the women who identified as current or past injectors reported that they believe they contracted hepatitis C through another means, such as a medical procedure or piercing. Some of these current and past injectors also reported that they did not know the source of their infection. The women who had never injected drugs reported that at least initially, on occasions, others assumed that they had. Most of the time, they were able to convince these others that they had actually never injected but had to provide an account of how they did in fact acquire hepatitis C to lend credence to their defence against the injector label being applied. These women reported that once others realised that they were not current or past injectors, they were treated more favourably, with more compassion and care. However, they were not always believed when they informed others that they had not injected drugs. Jessica reported that her GP, who diagnosed her hepatitis C, appeared not to believe her when she told him that she had never injected and assumed that she had loose morals.

*My GP, he tried to make out I was a bit of a lass. *Jessica

However, because others often make the assumption that because someone has hepatitis C, they are current or past injectors, women who have never injected also limit who they disclose their hepatitis C status to. As Kate demonstrates, even though she had never
injected, hepatitis C still carries with it notions of pollution and blame. However, she indicated that there is a greater element of blame if contracted through IDU.

Regardless of how you contracted it, I don’t think that should be an issue, like I don’t even think really, I don’t even know whether I told the doctor how I got it. But I really don’t think that he [doctor] should have treated me [better], you know. Either way, so, yeah, I was, I felt bad, like you do feel a bit, oh, you know, what an awful person you are, to have this, you know. You feel dirty, you really do. Even though you’ve done nothing to really deserve it, you, and I guess I don’t tell many people, and I’ve never told anyone in my workplace either. Kate

Disclosure of hepatitis C

The key problem associated with disclosing hepatitis C is that it usually also involves disclosure of IDU, which is often a bigger issue than the hepatitis C itself. Many women reported that they wanted to be able to disclose their hepatitis C status in a range of situations to different people, but their fears of what might happen if they did disclose prevented them from doing so. As a result, they felt guilty about not telling people and were constantly worried about their ‘big secret’. Fiona for example, reported that she wished she could talk to her flatmates and friends at college about her hepatitis C and drug use. However, because of the social stigma attached to hepatitis C, she feared that instead of the support she needed, she would actually experience rejection.

Abby reported that she would like to disclose her hepatitis C status at work, where she prepared food. She felt guilty about not telling her colleagues but feared she would lose her job if she disclosed her hepatitis C, because of the infectious nature of hepatitis C and the social stigma associated with the virus.
I was worried to work in this job with the food. I was worried because I didn’t want to infect anyone else, and if I got a cut, how am I going to explain it to them? You can’t go telling everyone.  
Abby

Effects of disclosure

Several women reported how disclosure to their family and friends was often met with concern and confusion, as well as many questions, particularly about IDU. However, once the risks and the virus were explained, most families and friends were reported to be concerned and supportive. Lindsay, however, was rejected by her family because they assumed she was a ‘junkie’ and as such, was a bad and undeserving person who they did not wish to be associated with because she would bring shame upon them.

I’m just a no good junkie user scum that basically shouldn’t be alive. The family think I am just junkie scum. Yep, I’ve told her [mother] once I’ve tried, and most teenagers try drugs whether it be pot, speed, heroin, once in their life. I know mum has tried pot. I know dad has tried pot when he was young, he doesn’t now. I said I’ve tried it once but don’t want to do it again. But mum just thinks I’m junkie scum and now dad thinks I’m junkie scum too because I’ve done it once, once that they know of. Lindsay

When they have disclosed their hepatitis C status, some women reported others to overreact because they feared infection. The confusion surrounding transmission risks of hepatitis C resulted in others isolating themselves from people with hepatitis C and some women reported others going to extraordinary precautions to prevent risk of infection, such as disinfecting the whole office where they worked. This contributes to the sense of isolation and pollution that many women with hepatitis C feel. One of the women who worked for a drug user support group told of an incident reported to her by a client.
We got a call here from a woman who worked in the public service and she disclosed to her employer that she was hep C positive and the bosses reaction was that they had to clear a whole afternoon, everybody had to clear their schedule from one pm to four pm. She wasn’t actually allowed to take part in the cleaning up. She had to sit at her desk while everybody, all her colleagues were busy sterilizing everything with disinfectant. She eventually left that place, I think it was three weeks she said, off the top of my head. Because she just couldn’t put up with it anymore. After the disclosure you know, she would walk into a room and overhear conversations like, ‘oh my God, I’ve been to the doctor. I had to get tested, now I have to wait three months now, because I used her coffee cup one day.’ So people are running off to get tested because they have used the same coffee cup as her.

Some women reported that a doctor had refused to treat them once they disclosed their hepatitis C status. This was very distressing, as Gemma described:

I went in for laser surgery last year on my cervix. I had a student doctor in there giving me the shot to put me to sleep, when he said asked me if I had hep C and I said, ‘yes I have hep C’, he didn’t want to give me my needle. Like, he just backed away, ‘nah I can’t give it to you, get someone else to do it.’ He was really weird and hurried, and my …. I started to cry and I was nervous as it was and like, because I started to cry the doctor who was doing my laser surgery [then became involved]. Gemma

Other women reported that when they disclosed their hepatitis C status in hospital, they were assumed to be drug dependent and as a result were denied pain relief and other medications they needed. Julie reported that this has been a problem for so many injectors that many have been advised not to disclose their drug use to hospital staff by other injectors and user support groups in order to reduce this type of discrimination.

When it came to administering the drugs, the anaesthetic people made a smart arse comment. Because I was freaking out about it not working, and it didn’t really offend me that much but yeah, that’s what comes too, having to take drugs in hospital. And I’ve been told not to tell them in hospital, that you are a drug user, or they will hold the drugs back. Julie
The women reported that when they disclosed their hepatitis C status to people who were aware of the transmission risks and were generally well informed about hepatitis C, then there were rarely negative reactions. However, medical practitioners were often expected to understand the risks and nature of hepatitis C, but the data here indicate that many either do not understand, or they act because of moral issues relating to the IDU with which it is associated.

For women who already have weak social networks, the threat of rejection is particularly frightening and distressing. Many women reported that having to keep their hepatitis C and IDU secret was a huge strain and a constant source of worry. However, they expected the consequences of telling others would be far worse than the stress they experienced in keeping it secret.

**Strategies of disclosure**

The women reported having different approaches about who to disclose their hepatitis C status to. Some women reported that they had a policy of telling lots of people, friends, family and medical professionals. Mostly, these women did so in an effort to reduce any risk of transmission of hepatitis C, but also to gain support in some cases. Other women reported telling very few people because they feared rejection, judgemental attitudes, questions and discrimination.

The majority of women reported that they disclosed their hepatitis C to select people. These are people who they expected would not react badly when told, nor be overly worried about either themselves, and those people they perceived needed to know, such as a dentist or obstetrician. Most women reported that they disclosed their hepatitis C, but only people they could trust because they expected them to understand. Professional
people who were expected to understand and not judge or reject them are medical staff at sexual health clinics, drug treatment centres and hepatitis C clinics.

Personal friends were generally only disclosed to if they had a good and trusting relationship. Most importantly, the friend must know them well enough that they do not assume the person telling them they have hepatitis C possesses all the negative characteristics associated with it. People who know them well know the many aspects of their life that define their actual social identity, unlike their presumed, or apparent social identity that others who do not know them so well see.

Janice reported that she wished she did not have to keep her hepatitis C and IDU secret from her non-injecting friends and her GP and dentist. However, because she has heard so many stories about the discrimination people have experienced when they have disclosed their status with good intentions, she did not feel guilty about this decision. Like mothers with HIV, Janice managed information about herself in order to maintain her social identity as a ‘good mother’, but recognised this is not an ideal situation (Ingram and Hutchinson, 1999).

I’m not an out-there type person you know telling the girls, yes I’m an ID user and yes, I’m hep C positive. Yeah, I don’t it’s not something that I [disclose]. But I mean, I do know women that are very out there about it and suffer discrimination from it all the time. If I don’t tell anyone then I can’t suffer any kind of side effects. Well, I mean obviously, I’ve got friends who are like me, are hep C positive, who are injectors. So I guess um, it’s just very difficult for me sometimes. I feel like I have got this deep dark secret, like when I am with other women, like my usual friends.

Janice

Other women also reported only disclosing to select people because of their fears of the consequences.
I’m sort of scared now I’ve told people. Like, I think they need to know. Straight away, they’re gonna think other things. Like, ‘oh she’s been using’. When I tell people, I tell them I got it another way. _Abby_

Straight [non-injecting] people I wouldn’t tell unless I needed to. Because they don’t know, and also because it immediately identifies you as an IV drug user, I think, even though they say you can catch it other ways. _Emily_

Many women reported that they felt comfortable disclosing their hepatitis C status to other injectors because usually the bad reactions that accompany hepatitis C disclosure were because of the IDU it is associated with. Among injectors it is ‘normalised’ (Goffman, 1963; Lupton, 1999). Once the deviance is removed, there remains only concern about risk of infection, which injectors generally have a good awareness of (Southgate and Weatherall, 2003).

In situations where others are already aware of someone’s hepatitis C status, or it is important for them to know of it, some women reported that they tell others that they acquired hepatitis C from a non-IDU source. This is to reduce the blame that is placed upon them in acquiring hepatitis C and was expected to result in more favourable treatment.

Now I just tell people I got it through tinea from the bottom of my feet and at the boarding house where I was living. It is very rare and that’s what I told the doctors and they said it’s very rare, they had never heard it, but it was possible. So I just use that excuse for everyone because they don’t need to know why I chose [to infect herself with hepatitis C]. _Lindsay_

Most women had a story to tell about a negative experience they have had when they disclosed their hepatitis C status. However, they also acknowledged that this is not always the case and many people are fine and in fact, some are very understanding about it.
Some women reported never having experienced a bad reaction when they had disclosed either their hepatitis C status or IDU. However, every woman knew many stories of friends who had had negative disclosure experiences and so they were all aware of the risks of disclosure.

Some women reported that they believed they were treated well by health care professionals because they were very open and honest about their hepatitis C and IDU. In being so open, they did not indicate that what they had done was in any way shameful, and as such provided fewer opportunities for discrimination.

**Hepatitis C and social relationships**

Some women reported that they felt as though hepatitis C would present a large barrier to new relationship formations, particularly if the relationship was with someone who was not an injector. Participants reported that other injectors were usually fine about it because they knew the risks of transmission and so many people with it that it has been somewhat normalised.

For women like Julie, this may restrict their ability to get out of the IDU network and into the ‘straight world’, as Taylor (1993; 1998) reported. Julie explained that she and her partner were both injectors and both had hepatitis C. However, she did have other ‘straight’ friends to whom she had not disclosed her hepatitis C or injector status. Julie reported that leaving the IDU world and entering the straight world was proving very hard for her because she would have to leave behind her friends, partner and sources of support and face judgement and rejection by the straight world. The stigma of hepatitis C, and in particular its association with IDU, can restrict some relationships and actually sever some.
The street-based, generally homeless or transient, women who were recruited around Kings Cross reported the high value of the support of street-based people living around Kings Cross. These women also valued highly the support they received from the drug treatment centre, the Kirkton Road Centre, and how this allowed them to develop support networks by creating a safe place to meet other people with similar problems who are non-judgmental.

In attempting to reduce the risk of transmission without disclosing hepatitis C, relationships can become strained. For example, if someone with hepatitis C does not allow someone else to use her toothbrush or injecting equipment after she has used it, this situation may require her to disclose her hepatitis C status to explain why others cannot use her things. However, the risks associated with disclosure may appear to be greater than the risks that hepatitis C transmission involves. If hepatitis C were not stigmatised in the way it is, or so closely associated with IDU, then this would not be the case.

The effects of hepatitis C on intimate relationships is dealt with in greater detail in the next chapter.

**Diagnosis of hepatitis C**

The women described many different experiences of being diagnosed with hepatitis C. Similar to the findings of Loxley et al (2000), the women in this sample reported varied responses to a positive hepatitis C diagnosis. Some women described feeling shocked and confused when diagnosed. Their initial reaction to diagnosis was associated with their injector status and the information and counselling provided by the diagnosing medical professional.
Women who had never injected, such as Karen, and those who did not strongly identify as injectors, even though they may have injected at some point, were most likely to report feeling very distressed when diagnosed. Women who had never injected usually had very little knowledge about the virus and knew no one else who had it at the time of diagnosis and as such, were far more confused and frightened.

Everything was going all right. I was on top of everything, I was really happy until they gave me the news about it and I was just, I’m still getting there, A to B and C type of thing every day. But it’s just rocked me, you know, because I’m thinking how did I get it, how? Karen

Jessica had some prior knowledge about hepatitis C because her partner had been living with it for some time before she was diagnosed. Jessica had never injected, and both she and her partner were very careful to avoid any risk of transmission from him to her. When she was diagnosed with hepatitis C she was very frightened and confused.

When I found out I had hep C it was the biggest shock of my life. Jessica

Valerie was a past injector, but reported that she believed she contracted hepatitis C from a skin piercing in Asia according to the points in time at which she was injecting, had the piercing and was diagnosed with hepatitis C. Upon being diagnosed Valerie was very upset and frightened.

I was so shocked, I was really, you know, like I was meant to meet a friend who was a social worker who I used to work with. I was meant to meet her for lunch and I rang her up and I said, ‘look I just can’t come.’ I am, I was devastated. I was really shocked. But it was huge, enormous. Valerie
Most women who were regular injectors had some understanding of hepatitis C before they were diagnosed because of the education campaigns they were exposed to at needle and syringe programs, drug treatment centres and publications produced by drug support groups. These women were, on the whole, less shocked by their diagnosis, like the women in the Temple-Smith et al (2003) sample, and often suspected they may have hepatitis C because they felt unwell or had engaged in risky behaviour. However, some regular injectors were still surprised and distressed about their hepatitis C diagnosis.

Amy had shared injecting equipment knowing that there were risks associated with doing so. Nevertheless, she and the person she injected with were very upset when she was diagnosed with hepatitis C.

It just went boom, it [hepatitis C] hit us like a rock. *Amy*

Janice, a regular injector, was not particularly daunted by her hepatitis C diagnosis. This was largely because she did not feel sick, but also because she knew lots of other people who also had hepatitis C who were asymptomatic. Additionally, she was aware that as she had been injecting for some time, there was a significant chance that she would have contracted hepatitis C. Other women who reported having many friends with hepatitis C also claimed that this reduces the impact of the diagnosis by making it appear more normal.

It was weird because I was thinking that I should have been more upset or more um, I should have been freaked out. But I wasn’t and I think the reason was ‘cos I just didn’t feel sick. I didn’t feel like I had some disease. I think the way I dealt with it was just … I guess I thought if I just didn’t think about it, it would just go away. *Janice*
Some regular injectors were also shocked by their hepatitis C diagnosis, because they had made efforts to reduce the risk of infection by not sharing needles. Although women who injected regularly had some knowledge of hepatitis C when they were diagnosed, they were still distressed, to varying degrees, and reported receiving little information or counselling from the diagnosing medical professional to calm their fears and confusion.

The women were tested for hepatitis C in a variety of settings. Most common were methadone clinics or other drug treatment agencies and GPs. Other settings included jail and notification from a blood bank. Three women were diagnosed when they were pregnant, two of whom through the many blood tests that they have as part of their antenatal care. Being diagnosed with hepatitis C whilst pregnant was reported to be particularly distressing and confusing. This is discussed in chapter nine.

Many women reported being advised of their diagnosis inappropriately, that is, without pre and post-test counselling, as also reported by Loxley et al (2001) and Gifford et al (2003). While pre and post-test counselling is not mandatory in Australia, it is recommended by the National Health and Medical Research Council (Loxley et al., 2001; 1997). The women in this study, as in WLHC sample (Gifford et al., 2003), reported that they would have liked to have received more information when they were diagnosed with hepatitis C.

The original [doctor] that tested me told me my status over the phone and they gave me no support they just … I rang them to get an appointment with the doctor. The doctor came on the phone and said ‘oh by the way, you have got hep C. I’ve got to go now, goodbye.’ And it left me pretty distraught even though I knew I had a high risk of getting it. The way I was told and I was at a bus station, a train station and it was just inappropriate behaviour from the doctor. *Lindsay*
Women who were diagnosed in the 1980s and early 1990s, when little was known about hepatitis C, were given very limited information. It is only in recent years that research has yielded any great amount of information and for this to filter down into care practice. Theresa is a past injector, and was diagnosed whilst she was still injecting and before hepatitis C was formally identified and was known as non-A non-B hepatitis (pre-1989).

I mean there just seemed to be gross ignorance. Like they couldn’t tell you what to expect, or what to do, you know, it was pretty bad. Theresa

Women who were diagnosed with hepatitis C more recently were provided with much more information and were more likely to receive pre and post-test counselling, which helped to reduce their distress. This corresponds with the findings of Gifford et al (2003) in which they found that women diagnosed with hepatitis C in the last five years were more likely to report receiving pre and post test counselling than those diagnosed earlier.

Women who reported feeling particularly distressed and anxious when diagnosed were often very fearful that they were going to die soon from hepatitis C. Much of this fear was reduced after having learnt more about hepatitis C. These women reported that the medical professionals who diagnosed them did little to set their minds at ease and that they had to actively seek out information from sources such as the Hepatitis C Council.

Now I had the idea from a GP who just took it, the thought of a junkie, got to have hep C. So because of that attitude, that idea and the idea that it has gone into me, thinking that automatically it was a deadly dangerous junkie disease that I was going to die of if I got. And I had got it. And I was going to die. So I don’t think, now, I am going to die, necessarily. Because I know that for a fact now, pretty much. I know there is a chance, I mean there is a five per cent or a 10 per cent chance that in 20 years time or in something like that [I could die]. Becky
Other women also highlighted the way that a more informed, less judgemental doctor who spent the time to explain things fully and answer their questions could have dispelled many of their fears. The few women who reported having such a doctor placed great value upon this resource.

She was really informative but I don’t think any other doctor would have been. They wouldn’t have been as bothered as her, being on the [hepatitis C] Council. *Hannah*

Hannah’s hepatitis C positive test result, after several years of feeling unhealthy, helped her to understand her health problems. It gave them meaning. However, although she had been a past injector, it also raised more questions, such as whom did she acquire hepatitis C from, how did she acquire it and why did she acquire it?

*It sort of explained [her poor health] and opened a can of worms a bit …* *Hannah*

Many women, such as Justine, reported their diagnosis to have been made worse by discriminatory treatment they received from medical professionals. This involved feeling judged because they had acquired hepatitis C, and because they were injectors, or assumed to be injectors. Medical professionals were reported to be disinterested and to not take time to provide adequate counselling.

*When I was diagnosed I was just treated like it was disgusting. I mean it’s, I have stories of, yes I can sort of say certain things that doctors did or whatever that people could go, ‘oh gosh that’s shocking,’ but also there is also the lesser or subtle things. Like when you go to a surgery and you know by the way the doctor looks at you and their incredible lack of attentiveness to you, that they are giving a message, that ‘I am not really interested’, you know. What their judgement is of you. I mean it’s intonation, in their expression, you know, people …… very clearly do those things.* *Justine*
Prognosis

Many women expressed anxiety about the uncertainty of their prognosis. That there is no clear epidemiology of the natural history of hepatitis C created a great deal of distressing uncertainty for the future. There was a great sense of fear among some women that they would die early from hepatitis C, even if they were currently asymptomatic. The most salient issue by far in regard to prognosis was the uncertainty of the prognosis, as Hannah describe.

I do have this [virus] that no one can shed any light on anything no matter how healthy, how unhealthy. Sure, they tell you that unhealthily yes, you will get it worse, and it is best to lead a healthy life. But no one has given any light on a healthy life. They say that smoking is pretty much a gamble but it’s not if you get cancer it’s now been really brought in the wind, it’s when. But with this, is it when, or is it if? And no one can tell me that one. Hannah

The effect of hepatitis C diagnosis on drug use

Two women reported that having hepatitis C had resulted in their drug dependence becoming worse, but for different reasons. When Becky was diagnosed with hepatitis C, she believed she would die relatively soon and not be able to have children because of it. Feeling incredibly hopeless, she returned to her heroin use. Becky did, however, soon regain control over her dependence by enrolling on and sticking to a methadone maintenance program.

Justine had been stable on a methadone maintenance program for some time. However, the lethargy she experienced, which she attributed to hepatitis C, led her to use amphetamines to allow her to function better. She eventually became dependent on
amphetamines, in addition to her opiate addiction, which she had managed to control through methadone treatment. Justine reported that she wants to have children, but would not do so until her health improves, which involves controlling her drug use but managing to function at an acceptable level. At the time of interview, Justine reported that without using amphetamines, she was unable to go grocery shopping without becoming completely exhausted.

**Hepatitis C related health care**

The general feelings about hepatitis C related health care were those of frustration and disappointment. Although people living with hepatitis are often offered tests to monitor their hepatitis C related health, the treatments for hepatitis C are limited and the little awareness that most people have about these treatments appeared to be, generally, very negative. Indeed, many of the women interviewed were not aware that any treatment for hepatitis C exists.

Overall, there was reported to be dissatisfaction with the hepatitis C related health care available. In particular, for many women, what was available to them from their GPs was a source of disappointment. It appeared that many GPs were not only unable to provide much help, but many did not want to treat people with hepatitis C. The few women, such as Hannah, who did report satisfaction with their hepatitis C related health care from their GP, placed great value on this. Becky, however, identified the failings of the GPs she had encountered:

> Like it’s not our job [GPs], that’s their opinion. It’s not their problem. It’s a shame that the hepatitis C people are often those people that the GPs don’t want to know. Becky
Most women reported their GPs had very little knowledge and awareness of hepatitis C, compared with medical professionals who work in the drug and alcohol field. Sometimes this resulted in the women receiving scant or misleading information, about hepatitis C and, in many cases, feeling discriminated against. Many women complained of not having had sufficient time to discuss their hepatitis C related issues with any of their treating medical professionals. Hepatitis C can penetrate an individual’s life in many ways and so the issues are complicated and require time to discuss and work through. Many women felt that GPs should do more for people with hepatitis C, as they are best positioned to provide on-going, encompassing, medical personalised care.

Women who had consulted a liver specialist also reported feeling frustrated because of the lack of information they were able to provide them with, particularly in relation to their prognosis. These specialists, by definition, have more knowledge and understanding of hepatitis C than GPs, and are able to provide more hepatitis C specific tests, such as biopsies. The role of the liver specialist was reported to be limited for many women because even they are unable to provide any kind of detailed prognosis and the treatments for hepatitis C are so limited. Additionally, unlike GPs the liver specialist were less likely to have a long term relationship with their patients, and thus less likely to be able to incorporate the many different aspects of their life into their assessment and treatment.

Hepatitis C related care from both GPs and hospitals was reported to be more accessible in inner city Sydney than regional areas. In the urban centres staff were reported to be more knowledgeable and familiar with people with hepatitis C and injectors, and confidentiality was perceived to be more secure. The interview data suggest that discrimination still occurs in inner city health services, although it was perceived to be less frequent and severe than in regional health services.
Emily had her child in a western Sydney hospital about 10 years ago. She believed that she would not have had such a bad experience because of her hepatitis C and drug use if she had attended an inner city hospital instead, where she perceived staff to be more experienced in these issues.

And so I just arrived at [X] hospital in labour and told them I was hep C positive and after my son was born I got this man in a suit come round to me. I was in a single room, I was isolated, which is fine, I understood why. But, you know, all the yellow stickers, the hazard stickers and stuff. And I had this man come in with a suit on and I thought… they said someone from infection control was around and I thought he was going to tell me that I was HIV positive, I really did. And he came in and sat down and it was all very serious and started to talk to me about being hep C positive, and he said and, ‘basically you can’t breastfeed,’ and I said, ‘why?’ And he didn’t answer me, he really didn’t give me an answer. And my son went through really bad withdrawal because he wasn’t medicated correctly. Because X hospital had very little experience with methadone mums and I was on 80 milligrams, like 16 mils, which was a relatively high dose and they did not know how much [drug] to give him, so he had convulsions. So they transferred him to [another hospital closer to the city] and as soon as he was medicated properly he was fine, he was put on a much higher dose of morphine. *Emily*

**Barriers to hepatitis C related health care**

There were reported to be many barriers to accessing hepatitis C specific health care. In particular, the stigma and discrimination associated with hepatitis C was reported to present a major barrier to obtaining hepatitis C related health care. For example, to see a liver specialist requires a referral from another doctor. Women who were not seeing a GP about their hepatitis C, as many did not for fear of discrimination, and they were also not in a drug treatment program had very limited access to these specialists. Becky highlighted how many people with hepatitis C may try to sever their links to drug treatment programs as their lives become more stable. However, because they still carry the social label of being a
‘junkie’, they may not have a GP they can go to about hepatitis C. As such, they are likely to experience barriers to the care that they need.

Based upon the interview data, accessing hepatitis C health care appears to be easier for people of higher SES, such as Theresa and Kate. These women were more able to articulate their demands, and questions. It also appears that women of higher SES living with hepatitis C are less likely to be discriminated against. Women of lower SES, especially street-based women with severe drug dependency problems, appear to have significant problems accessing hepatitis C related care. However, these marginalised women (in the inner city at least) are often in contact with outreach services. Women who have little contact with medical services, however, were possibly in an even worse position than some street-based women in regards to their hepatitis C health care.

**Segmented health care**

Several women reported that hepatitis C related health care to be problematic in relation to other aspects of their health. Most women had to see different specialist doctors for their different health concerns, such as drug dependence, obstetrics, and general health. As a result, these interrelated issues were each considered as separate entities, but in fact these issues should be considered in relation to each other, in the way they are experienced by an individual. Very few women were able to consult their GP in any detail about hepatitis C and how it relates to pregnancy. This was because many GPs were reported to not have sufficient hepatitis C knowledge, and others appeared to be judgemental. Becky was particularly frustrated by this segmented health care.
Believe me it makes it very complicated, specialists. The doctor is only paid to write the prescription at the clinic, is only getting paid to deal out methadone. The GPs are only getting paid to do things that GPs do, because specialists do things like hep C, The GP is sitting there saying, ‘this ain’t my job anymore’. How the hell do I get my liver specialist and my [fertility] specialist to agree or work out anything? Becky

The personal and social problems associated with hepatitis C were often reported to be far greater than the disease aspect of the virus. This requires care focussed upon the person, rather than the disease, which the medical model of care historically does not do well. GPs are well situated to provide on-going, supportive care, in addition to, or instead of that offered by liver specialists. GPs are in a more advantageous position to learn more about the person, their lives and their problems. They have a greater capacity to provide the support that is needed. GPs would be more able to incorporate hepatitis C with their other health issues, including pregnancy. However, the stigma attached to the virus, because of the associated IDU, was reported to prevent this from occurring in most cases.

Medicalisation of women with hepatitis C

Although for most people with chronic hepatitis C, the medical professional can do little to change their hepatitis C status, many people with hepatitis C have regular clinical tests to monitor their hepatitis C related health. The most common of these tests are liver function tests (LFTs), which measure how well the liver is functioning, and thus how badly affected it is by hepatitis C. The tests give a rough indication of what is happening to the liver. LFTs, as well as other tests, such as PCR or liver biopsy, are usually used to assess individuals for treatment with Interferon (Commonwealth of Australia and Australian Institute for Primary Care, 2001).
Hopwood and Southgate (2003) describe the process of medicalisation in which there is a changed sense of self among people diagnosed with hepatitis C as they become defined by the clinical are performed upon them. The medicalisation process, they argue, is ‘a tendency for patients following a diagnosis to incorporate medical information about their health into a shifting sense of self’ (Hopwood and Southgate, 2003: p259). This is supported by Faye and Irurita (2003), who showed that after being diagnosed with hepatitis C, individuals’ sense of self changed over time, incorporating hepatitis C into their lives. Cordoba et al (2003) found this medicalisation process to have a negative impact upon the quality of life of people with hepatitis C. In using clinical markers to recreate a sense of self, the social problems associated with living with hepatitis C are neglected. Evidence of this process in the interview data is detailed below.

Most women reported having regular tests to monitor their hepatitis C, usually LFTs. The women commonly referred to the results of these when explaining how living with hepatitis C affects their lives. Test results were related to how they had been feeling, or to the limitations their hepatitis C related health had on their daily activities. When they had been experiencing symptoms of hepatitis C or feeling generally bad, their test results usually concurred with this.

Up and down [LFT results], it varies yeah. Depends on the stress and the strain I am going through that week. *Amy*

I have always had within the completely normal [liver function] levels. So really I am quite healthy really. *Georgia*

Jocelyn had been very sick from hepatitis C and was in a clinical trial of new treatments for hepatitis C. Jocelyn reported to have been feeling better in recent weeks and associated this with the clinical markers used to assess her hepatitis C status.
Lots of things happened, so yeah I’m tired, I’m exhausted. You don’t want to [blame] it on the hep C but I guess it was. Because I feel a lot better now, now that my viral load has gone down so much, it was so high. Jocelyn

Several women associated their drug-taking and alcohol consumption, as well as other lifestyle considerations, with the results of clinical tests.

I did have a bit of tightness in my liver. I went and visited the doctor and I had never seen the liver doctor before. [He said my] LFT’s went through the roof, when I am injecting methadone syrup. Ellie

And because we [Dawn and her partner] don’t drink, my liver functions have been really good too. I don’t think I’ve ever had a bad liver function test. They’ve all been in normal range. Dawn

Resisting the medicalisation of hepatitis C

Some women rejected the clinical indicators that are often used to assess hepatitis C related health, as they perceived them to have little value or meaning, particularly when they were asymptomatic. In Justine’s experience, the test results did not relate well with how she had been feeling, and considering the other limitations of the tests, regarded them as having little if any value to her.27

Those liver function tests are hopeless. Because they tell you that your liver is functioning, not what stage of health or decay it’s in, the liver. And I don’t know how, and I don’t have much faith in how reliable they are. I mean I have had excellent results on my LFTs when my liver has been aching and I’m going, oh my God, I mean those sort of checks, they only come up problematic if you are in an absolute chronic stage. And I don’t have much faith in them, so I don’t bother. Justine

27 The limitations of LFT’s are acknowledged in publications available to both medical professionals and lay people. Booklets produced by the Hepatitis C Council of NSW (Hepatitis C Council of NSW, 2000) acknowledge the limitations of the tests, which tie in closely with Justine’s complaints.
Several women reported that they did not undergo clinical tests to monitor their hepatitis C. They chose not to because they feel that the results of these tests may redefine their identity and have negative consequences, in the ways described by Faye and Irurita (2003) and Hopwood and Southgate (2003). Theresa reported no longer having regular tests like she used to, as she saw little advantage in doing so. Like some other women, she declined further investigatory tests, such as a biopsy, as she felt reasonably healthy, and such a test may indicate otherwise and change her healthy identity.

Well I haven’t had liver function tests done for about three years, because they’re pointless, they can only tell you what’s happening on any given day. I haven’t felt affected enough by hepatitis C to have a biopsy. Theresa

Other women, such as Sally, also reported not having regular clinical tests for additional reasons. Like Theresa, Sally did not wish to monitor her health in this way, but also reported strongly disliking encounters with medical professionals, based upon her own and anecdotal discriminatory experiences.

I’m one of these people. I don’t wanna know. I’m not really overly unwell or anything so I just figure, denial. Well yeah, I don’t really want to know. I haven’t even had more tests, so I am not absolutely sure what is happening with my hep C but I should. I mean for all I know, I probably have AIDS. I just don’t like going to doctors and stuff. Sally

Conversely, a small number of women reported that they would like to have more clinical tests to assess their hepatitis C related health, in order to arm them with more information with which to make childbearing decisions. This is discussed further in the childbearing decisions findings section.
Hepatitis C and self-perception

In addition to the medicalisation process, whereby people with hepatitis C become defined by clinical markers, the women described other ways that hepatitis C made them feel, either because of the way people treated them because they had it or the way that they felt about having the virus itself. The ways in which others have reacted to women with hepatitis C because they have the virus, and the messages they send were internalised by some women. Sally explained that there is social pressure to donate blood, but having hepatitis C prevents one from doing so. Like several other women, having their blood rejected by the blood bank in this way contributed to the notion of being polluted, different and undesirable. This can impact upon the way individuals view themselves, their bodies and their sense of self.

It [blood donation] was done really publicly and it was seen as, you know, very wholesome good and charitable if you did. And if you didn’t, people really looked down on you. And there was always that thing of you know, being very conscious that you had hep C, or you might have other things in your blood, or something that you couldn’t give blood. And I think that sort of affects how you feel about yourself, or your whole body and blood the whole time.
Sally

Lifestyle changes

Most women believed that if they lived a ‘good’ healthy lifestyle, they would improve their prognosis, which resulted in them making changes to their lifestyle. Those who had made the greatest changes tended to be those who experienced hepatitis C related symptoms, which they associated with specific behaviours, such as drinking alcohol, not having enough sleep or taking drugs. These women have responded to both educational messages, but also to the messages that their bodies have given them in the form of symptoms. Women who reported not having made any changes to their lifestyle as a result of hepatitis
C often stated that they did not feel that there is any need for change because they had not experienced any hepatitis C symptoms, which were perceived to be an indicator that change was required.

Most women had made changes to their lifestyle based on advice from doctors, specialists, counsellors and leaflets. These changes included improving their diet, reducing or stopping drinking alcohol, reducing or stopping taking drugs, making sure they got sufficient sleep, reduced or ceasing sharing injecting equipment, changed working hours and starting regular exercise. A few women also started alternative therapies, such as acupuncture or using liver tonics and Reiki. 28

I don’t get stressed any more. I do yoga, meditation, you know, early nights, I don’t stay up late, just look after my body. And then the acupuncture as well. It’s a big thing [hepatitis C]. I used to work a lot of nights and I’ve stopped working nights now because of the effect on my body. Jessica

The women recognised the limitations that hepatitis C placed upon their health and their lives, and structured their lives around minimising the effects of the virus upon their health. This resulted in their lives becoming more structured and measured than they were before they acquired hepatitis C.

Other people have more time because their body’s not going to tire as quick and they can stay up and do assignments and stuff whereas I sort of have to be really on it and get things done each day I have to really plan my life I can’t go, oh I’ll just go and do it two days before it’s due and stay out. Because I know my body won’t do that, you know. Fiona

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28 Reiki is a Japanese form of alternative, or complementary therapy based upon healing energy.
For some women, the changes to their lifestyle had been dramatic, and have presented challenges to their identity. Hannah, for example, was known as ‘The Chardonnay Girl’, a nickname based upon her drinking behaviour. After changing her drinking behaviour considerably, her nickname no longer seemed appropriate, and as such her social identity had changed. When with friends, Hannah, with the help of her supportive husband, takes steps to prevent her friends from noticing a great difference in her behaviour, such as swapping glasses with her husband so that it appears she has drunk more wine that she had. Hannah also reported having ceased using recreational drugs and ensuring she had a healthy diet and took regular exercise. Hannah hoped that if she had treatment for hepatitis C in the future, then she may be able to regain her identity as ‘The Chardonnay Girl’ as she would be able to return to her previous way of life that was presently constrained by her hepatitis C.

Yeah, I’d love to [have treatment for hepatitis C]. Just get rid of it, because I may have a different life again. I was always called The Chardonnay Girl! As I get a bit older, I’d like to do a winery and I would like to, perhaps, just be able to, when I felt like having a drink, as I said, never a big drinker, but just to be able to know that it’s okay to have that glass of wine without knowing that it could be to my death us do part. Hannah

A small number of women stated that it was not just changes to their physical health that were necessary. They also made changes in their attitude towards living with hepatitis C. They explained that if they allowed themselves to think they are sick then that would happen. If, however, they remained mentally strong, they would be able to fight off the virus better. Jessica described the mental strategy she used to prevent physical symptoms of her hepatitis C. She believed that if she did not allow herself to accept that she was physically ill, then she would not become so. She was determined not to let hepatitis C dominate her life in that way.
That's the difficult thing. I have this approach to illness I could go around going, 'oohh', you know, 'I'm tired, oh that must be the hep C.' And to me that complicates it more. So I believe if you are positive and you treat your body well and you are going to cure it and you will get rid of it. That's why I do the acupuncture. Just be positive, like I'm not ill, you know. I think it just makes them worse. When they actually have to do more they are better for it.

Jessica

There were also some women who were aware that their current behaviour was having a serious negative impact upon their health, but were not planning to change their behaviour. This was the source of some anxiety among these women, some of whom experienced painful symptoms, which they attributed to their drinking or drug use. Emily continued to drink alcohol although her doctors advised her not to.

I haven’t been sick. I actually had a liver function test not so long ago and it was raised but not bad and it’s because I’ve been drinking in the last 12 months. And up until then I wasn’t much of a drinker. And he [her doctor] said, you know, it’s because of your drinking and if you stop drinking it will go back to normal. I’ve started drinking alcohol again and that concerns me, that I’m going to damage my liver and it’s stupid. You know what I mean? It’s stupid for anyone to do it but I think more so for me because I’m hep C positive, it’s something that I really shouldn’t do and I’m doing it. Emily

Health and morality

There is also a moral component to these lifestyle changes. Kate described the way that she thought she would stay healthy if she led a ‘good life’. A ‘good life’ implies being a good person and conforming; doing what one is told to do and abstaining from what you are told not to do. In adjusting her behaviour, Kate constructed a new identity. Kearney (1995) found that drug-using pregnant women made positive lifestyle changes, including starting drug treatment, which served to demonstrate they were doing something to change their identity. This implies an association between poor moral character and ill health, which
suggests that there exists a notion of blame for ill health, as has been documented for other
diseases, particularly HIV/AIDS (Epstein, 1995; Lawless et al., 1996; Miles, 1991; Nelkin

That some illnesses are indicative of who you are, I don’t know, it’s a moral judgement about an illness. Then you have to make the
net much wider and accuse people that smoke or eat too much.

Jocelyn

Kelly reported that her doctor treated her as though she was to blame for having hepatitis
C, and for him to have treated her judgmentally.

You know ‘sucked in, ha-ha, you got yourself infected, you brought it upon yourself, so therefore you fucked yourself up’, that
was the sort of attitude. Yeah, just general distaste from them [medical professionals] towards me. Kelly

Hepatitis C virus carries with it a notion of blame because of the deviant behaviour with
which it is associated. Society may perceive that if they had not injected drugs, most of
these women would not have hepatitis C. As such, they are at least partly, if not wholly
accountable for their disease.

Kate, who had never injected, demonstrated that some moral component exists even for
those who have never injected and have acquired hepatitis C through some other route.

I hope if I live a good life, like you know, not consuming too
much alcohol and stay healthy, hoping that it will, [stay] like just as
healthy as I am now. I’ll be happy if I’m as healthy as I am now
in10 to 15 years time. Kate
Hepatitis C and social roles

Some women were unsure whether or not they had experienced acute or chronic symptoms because of the malaise associated with their drug taking. Because of the unclear nature of the symptoms associated with hepatitis C, it is difficult to distinguish between hepatitis C symptoms, withdrawal or general ill health associated with drug use.

Well it’s really hard to know what’s hep C and what’s not. ‘Cos you don’t go to doctors, you know. You get tired all the time and people say fatigue, and then you think, well people get tired they work. It’s really hard to tell when you are on methadone, when you are using drugs as well and you have got hep C. What is the hep C and what is not because you are so used to, sort of feeling like up and down. You are so used to it when you are using drugs, feeling either sick or not sick or, you know, all the hanging out and stuff and it’s really hard sometimes. Sally

Hepatitis C symptoms were reported to be highly variable. Some women had experienced severe and debilitating symptoms, while others reported never having experienced any symptom. Only a minority of women reported experiencing severe symptoms, but a large proportion experienced fluctuating minor symptoms. Most women did not consider themselves to be ‘sick’ because they had hepatitis C. They based this assessment on the presence or absence of symptoms and the degree to which their hepatitis C symptoms currently prevented them from performing particular roles or tasks, in addition to the results of tests that monitor their hepatitis C related health. Parsons’ (1951) sick role is based upon an individual becoming so sick that they are unable to perform their normal daily activities. The concept of the sick role remains at least to some degree central to contemporary understandings of health and illness. This is demonstrated by the women in this sample who assessed whether or not they were sick on the degree to which their symptoms prevented them from fulfilling their normal social roles.
I mean I am aware of it, you know, I hope that I am very aware of how easily it can be transmitted. I'm very aware of that. But I don’t really see myself as sick, maybe because I don’t feel sick, you know. When I went through that period of throwing up, that really frightened me, and that worries me a bit. *Tammie*

I just know that I have got this virus in my liver. You know, I don’t feel sick. I wouldn’t say I was sick. *Georgia*

The women who reported experiencing hepatitis C related symptoms described the fluctuating nature of the symptoms. This created identity problems because at times they were perfectly capable of fulfilling their daily tasks but at other times were incapacitated. This means that like many other chronic diseases, hepatitis C does not fit into Parsons’ conception of the sick role. Although symptoms can be severe and debilitating, they are fluctuating, so that while they may be serious at a particular time, the individual may in fact function well most of the time. By far the most common symptom reported was lethargy, of varying degrees of severity. This symptom presented problems because it directly limited what they were capable of doing each day. Consequently it also impacted upon employment (Platt and Gifford, 2003) and social activities (Conrad et al., 2001; Crockett and Gifford, no date; Gifford et al., 2003; Miller et al., 2001; Rodger et al., 1999). Jessica highlighted the ways in which the fluctuating nature of hepatitis C symptoms created problems because they do not fit into Parsons’ concept of the sick role, which determines a person’s entitlements to financial and other forms of assistance.

I might not get ill for 20 or 30 years, so it is a long term chronic illness but the nature of it is up and down. You could be really good for like a week and then you could be ill for a couple of days but because of that you can’t work because every two days out of a week you are ill. You can’t take a job because you don’t know which two days it’s going to be, so then you have to try and get benefits, sickness benefits, which they don’t really want to give you because they view you as quite well, you know. *Jessica*
When reporting on the severity of their symptoms, several women referred to the extent to which the symptoms would prevent them from doing things, such as shopping or even getting out of bed and managing to walk.

I can’t physically work. I couldn’t work an eight hour day and sort of feel reasonably okay towards a few hours, you know and just doing a small task like going shopping or something. Justine

Gemma felt that hepatitis C had been a major contributor to her not being able to work.

Ah, a little bit but it’s hard for me to get up every morning. Like not so much I was tired, I was just drained of energy, like as soon as I got home I wanted to sleep and whether I got eight or 12 hours [sleep] every day because of my hep C. I understood that it would do things to me like that but I didn’t think it would push me out of the workforce. Gemma

Some women indicated that through testing positive for hepatitis C antibodies, they had become medicalised and although they did not experience any debilitating symptoms, they possessed a social label that indicates that they were in fact sick to some degree.

Summary: Women’s social experiences of living with hepatitis C

Women’s social experiences of living with hepatitis C were reported to be varied. Stigma and discrimination were central to many social experiences of living with this virus, and much of this was shaped by the strong association of the virus with IDU. The reports in this study concur with extant literature on gendered experiences of health and illness, stigma, and recent findings of a large cross sectional survey of women living with hepatitis C (Gifford et al., 2003; Temple-Smith et al., 2004). The consequences of this stigmatisation can be significant and contribute to the social exclusion of many women living with hepatitis C, whilst denying them the support they require. Although for some women the physical symptoms they attribute to hepatitis C are sometimes debilitating and sometimes
painful, for most women living with the virus, the social problems associated with hepatitis C exceed the physical manifestations of the virus.

The women in this sample reported hepatitis C to redefine their social identity. The data indicates that hepatitis C creates a polluted filter through which all other aspects of their lives are viewed, resulting in their other social identities being tainted with the deviant identity, as described by Jones et al (1984). As a deviant identity, hepatitis C is powerful and often overrides other social identities (Schur, 1983). As Pfuhl and Henry (1993:p123) claim, a deviant identity is a ‘master status’.

This chapter has explored the multiple social realities of women living with hepatitis C. This has been done in great detail in order to provide rich contextualisation of childbearing decisions and motherhood relating to hepatitis C. The next two chapters present the findings of this study in relation to childbearing decisions and experiences of motherhood.
Chapter 9: Hepatitis C and Childbearing Decisions

Most women reported that hepatitis C was a factor, to varying extents, in their childbearing decisions. For some women, hepatitis C was just one of the factors to consider and weigh up in relation to the many other factors involved in childbearing decisions. For other women, hepatitis C was a major concern in relation to childbearing, and for a minority, was perceived to be a key factor, potentially preventing them from having children, or limiting the number of children they have. For others, it potentially affected the timing of births, rather than whether or not they have children.

The ways in which hepatitis C was reported to present concerns and problems for childbearing were varied. Hepatitis C has the potential to influence childbearing decisions both directly and indirectly. The ways in which hepatitis C was reported to influence childbearing decisions are outlined briefly below, and are discussed in full in subsequent sections.
Direct influences of hepatitis C on childbearing

Some women reported hepatitis C to directly impact upon their childbearing decisions in the following ways:

- Concerns about the risks of vertical transmission of hepatitis C to their baby;
- Current poor physical and emotional health relating to hepatitis C;
- Concerns about the risk of future poor health or early death as a result of hepatitis C;
- Childbearing conflicting with treatment for hepatitis C.

Indirect influences of hepatitis C on childbearing

Some women reported hepatitis C impacted on their childbearing decisions in less direct ways. Overall, the multifaceted effects of having hepatitis C on their lives made childbearing more difficult by influencing many of the factors that are taken into consideration when making childbearing decisions.

Most women reported experiencing discrimination based on the stigmatised nature of hepatitis C. This was reported to be a major issue that impacted upon the other factors they took into account in their childbearing decisions. Other factors were influenced by hepatitis C because of the physiological effects of the virus, some by only the social effects, and some were affected by a combination of the social and physiological effects of hepatitis C. Some of the ways in which hepatitis C can affect childbearing decisions are outlined briefly below. Several of these issues are likely to be considered by women in the general population. However, living with hepatitis C can increase the importance of these issues.
The childbearing decision making factors that were affected by hepatitis C included, but were not exclusive to:

- Lack of social support;
- Having a suitable partner to share parenting responsibilities;
- Age;
- Existing children;
- Drug dependence and methadone treatment;
- Financial security and employment.

The women reported a range of other socioeconomic factors that they considered to be important in their childbearing decisions. Most women mentioned many similar factors, however, the weighting they placed on these factors varied, according to their personal situation. The following section examines each of the ways that hepatitis C was reported to influence childbearing decisions in greater detail.

**Vertical transmission of hepatitis C**

The majority of the women were aware of the risk of vertical transmission of hepatitis C during pregnancy and childbirth. They were able to express this as a percentage; for example, there is a five per cent risk of vertical transmission. Their reports on what they believed the exact figure to be varied. Most women, and the medical professionals they had discussed the issue with, considered the risk of vertical transmission of hepatitis C to be low or very low.

I was told five to seven per cent, so I was thinking maybe my odds were pretty good. Sarah
It’s great to have a child that hasn’t got it [hepatitis C] and I’ve got one already, and the odds are very small that you can pass it on to your child. *Kate*

Despite the overall perception of the risk of vertical transmission occurring being low, the data indicate this to be an important concern in relation to childbearing.

Of course, all I can think about is hopefully my child doesn’t get it and I can’t even go there to think, because I’ve read the book and it said that most of them get it until 18 months and then it goes away. *Hannah*

Sally reported that her concerns about how her hepatitis C status might affect a child had contributed to her decision not to have any children.

Concern about the health of the child. Even though you know rationally that there is probably a small chance of transmission [of hepatitis C]. So it’s not high, but there are also the things about the methadone… *Sally*

A minority of women reported the risk of vertical transmission to be the most important consideration in their hepatitis C related childbearing decisions. For these women, although they reported that they perceived the chance of vertical transmission occurring to be small, it was a major concern for them, particularly in combination with other factors. Fiona already knew she had hepatitis C when she became pregnant. After much consideration, she decided to terminate the pregnancy, a decision which she reported to be largely because she had hepatitis C. Part of the reason for this was her fear about vertical transmission of hepatitis C.

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29 This quote also demonstrates that although Hannah had read the information she has been provided, she did not fully understand it. She was not quite right when she states that ‘most of them get it until 18 months and then it goes away’. In fact, babies are born with antibodies for hepatitis C. It is only those who have acquired the hepatitis C virus who continue to test positive for hepatitis C antibodies. This suggests that detailed counselling to ensure an adequate understanding of hepatitis C related issues is required.
I wasn’t in a position, but more importantly I was very scared of having hep C and how it would affect the child and also, just different things… I got really scared and I didn’t have anyone to talk to and he [father of the baby] found it really hard to talk about. *Fiona*

The overall risk perception of vertical transmission was variable. Georgia believed the risk of vertical transmission to be 20 per cent; much greater than most of the other women believed it to be, and higher than what is normally believed to be the case in Australia (Ceci et al., 2001; Hillemanns et al., 2000; Michielson and Van Damme, 1999; Okamoto et al., 2000; Resti et al., 1998; Spencer et al., 1997). Georgia considered this higher risk of vertical transmission to be acceptable. This may be influenced by her strong desire to have a child, which influenced her risk acceptability perceptions, as risk is socially constructed and determined by social values (Cohn, 2000; Douglas, 1985; 1994; Lupton, 1993; 1995; 1997; 1998; 1999; Rhodes, 1997; Rhodes, Lilly, Fernandez, Giorgino et al., 2003; Rhodes and Quirk, 1998). Risk is not a simple objective calculation or assessment of the odds of something occurring (Caplan, 2000). A decision that carries risk may be perceived as irrational based on rational decision-making models (Loxley, 1998). Such decisions appear irrational because most risk models treat risk as objective, and neglect the contextual factors and social values that determine risks and risk acceptability. Georgia placed a great deal of value on having children, which is socially driven because of the centrality of motherhood to female identity (see chapter five).

*It seems like the rate of transmission is 20 per cent, which is pretty low. When I weigh it up, I will have a child. Georgia*

Other women considered the estimates of the risk of vertical transmission, which ranged between 4-15 per cent, to be sufficient to cause considerable concern and for a small
minority, possibly high enough to prevent them from having children. As well as incorporating the risk of vertical transmission into her childbearing decision, Georgia compared the risk of vertical transmission to that of having a baby born with Down’s Syndrome. However, the consequences of a child living with Down’s Syndrome are usually more complex and serious than those with hepatitis C. It is possible that Georgia perceived childhood hepatitis C to be more severe than current opinion suggests.

I have probably got more chances of getting a child with Downs Syndrome. Georgia

Some women reported to not be overly concerned about the risk of vertical transmission, but that they did take it into consideration:

I have been told that [the chances of] transmission are so small, especially if you are healthy, your child is not likely to suffer from it. Well it didn’t stop me [from having children] at all. Veronica

Dawn and her husband had initial concerns about the risk of vertical transmission. They consulted several different doctors about the risk of vertical transmission and they considered the information they received from these doctors to be credible because they selected doctors who were familiar with dealing with pregnant women who were injectors and/or have hepatitis C. They concluded that the risk of vertical transmission was sufficiently low as to not warrant too much concern.

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30 The odds of having a baby with Down’s Syndrome are actually significantly less than the risk of vertical transmission of hepatitis C. The prevalence of Down’s Syndrome in the general population is about 0.15 per cent (Bell, Rankin and Donaldson, 2003; Holding, 2002; Wright and Bray, 2000).
31 See chapter one for a discussion of childhood hepatitis C.
Lack of knowledge and understanding of the risk of vertical transmission

A minority of the women had a poor knowledge and understanding of the risk of vertical transmission of hepatitis C. Among these women, the risk of vertical transmission was generally over-estimated, rather than under-estimated. Additionally, some women assumed the risk of vertical transmission of hepatitis C to be similar to that associated with HIV. This may be because the risks associated with vertical transmission of HIV/AIDS are better known through education campaigns and the media. Hepatitis C has not received such attention.

Sharon’s statement below indicates that she believed that there to be a significant or high risk of vertical transmission, when she speaks of her daughter.

I have it, there is a good possibility she [daughter] has it.

Sharon

Most, but not all, of the women who had poor knowledge of the risks of vertical transmission tended to be of lower SES, and more likely to be drug dependent. Georgia was an exception to this, as a middle class woman working in a responsible job; Georgia appeared to have quite poor knowledge of the risk of vertical transmission and childhood hepatitis C.

I’m not sure how it works, is it like AIDS or something?

Jean

Several women indicated confusion about the way their hepatitis C diagnoses are explained to them, as also found by Southgate and Weatherall (2003), and this impacted on their
perception of vertical transmission and childbearing with hepatitis C in general. The most common test for hepatitis C infection tests for hepatitis C antibodies, rather than the actual virus (Commonwealth of Australia and Australian Institute for Primary Care, 2001). The PCR tests for the actual virus, but these are expensive and usually reserved for patients considering undergoing Interferon treatment (Commonwealth of Australia and Australian Institute for Primary Care, 2001). Because Kylie had been informed that her baby, who she was pregnant with at the time of interview, would be born with antibodies for hepatitis C, she believed that this meant the child was protected against hepatitis C. Although this demonstrates logical thought, as antibodies are usually presumed to be an indicator that the body has fought off an infection, this is incorrect in the case of hepatitis C. Babies born to hepatitis C positive women are born with hepatitis C antibodies (Moyer, Mast and Alter, 1999). Most babies test negative for these antibodies within 18 months after birth, and have not acquired the virus. A small proportion of babies continue to test positive for these antibodies, and these are the babies who have contracted hepatitis C. Confirmation that vertical transmission has occurred is through testing for the hepatitis C virus using a PCR test (Spencer et al., 1997). This confusion is potentially dangerous because if a woman believes her child to be immune to hepatitis C, she may not take steps to prevent her child from contracting hepatitis C from her through household, or other routes of transmission.

So [unborn child] would have an immunity [to hepatitis C infection], is that right? Kylie
Perception of risk of vertical transmission when diagnosed during pregnancy

Three of the women interviewed were diagnosed with hepatitis C whilst pregnant. One woman was diagnosed during pregnancy about 10 years ago, one approximately five years ago, and the other woman six months preceding the interview. For two of these women, the risk of vertical transmission was reported to be a major concern and a source of great anxiety and distress. The two women who were diagnosed with hepatitis C most recently reported that they were reassured that the risk of vertical transmission during gestation, birth or breastfeeding was small. This was not the case, however, for Emily, who was pregnant when she was diagnosed with hepatitis C approximately 10 years ago. Upon discovering she was pregnant, Emily began methadone treatment, where she was tested for hepatitis C.

It was when I went to get on methadone, the methadone clinic, they had, like, blood tests. HIV and all the STDs, like, a range of that. I had a couple of false negative readings, a couple of negative results, so at first I thought I didn’t have it [hepatitis C] and then it came back positive and, [I was told] nothing about how it would affect my child. Nothing about how it would affect me. Emily

Kelly briefly considered the possibility of terminating her pregnancy because she was diagnosed with hepatitis C when she was about 19 weeks pregnant with her second child four years ago, even though she believed the risk of vertical transmission to be lower than is currently advised.

[Q: So how did you react at the time?] Oh pretty freaked out. Bit surprised. But then you know, I was half surprised and half not, because what with my experience [of IDU] and that. And really worried about whether I was going to infect [unborn child] and whether I’d infected my son. They told me that there was a two percent, I think it was about two percent, chance of infecting while carrying, more chance of infecting during birth. I could have got a
termination on compassionate grounds or whatever, but I chose
not to. They would have had to induce her, and she would have
had to have been born. So I didn’t fancy doing that. Kelly

Abigail was diagnosed with hepatitis C whilst pregnant at an inner city hospital a few
months preceding the interview and appears to have been given more accurate information
about the implications of this for both her and the baby.

It was only when I was doing the whole pregnancy thing that they
came in and said, well they started talking to me as if I already
knew I had it. And it was like, oh no, and they went, ‘oh yeah, well
actually you’ve got antibodies’ and it was like, ‘ah too late, oh what
a shame….’ Well they sort of like offered to talk to this person and
that person and stuff, but it wasn’t so much counselling, but just
letting me know that you still can breastfeed and all that, and just
how to deal with it from that kind of perspective, and that mostly
you don’t pass it on through the pregnancy. Abigail

These limited reports indicate that over time, it is becoming less distressing to be diagnosed
with hepatitis C during pregnancy. This is most likely due to an increased knowledge about
the risk of vertical transmission and other aspects of hepatitis C, allowing for the
diagnosing doctors and other medical professionals to be able to adequately counsel
women in this situation.

**Reducing the risk of transmission**

Although the women in this sample were usually informed of there being a small chance of
vertical transmission occurring, they wanted more information on risk factors that would
influence transmission.
They wanted information on ways in which they could reduce the risk of vertical transmission, such as having a caesarean section birth, or reducing their intake of foods or chemicals that might be identified as increasing the risk.

I was open with my obstetrician and I said, ‘I’ve got hep C, I don’t want the baby to get it’. I said, ‘if there are ways that we can reduce the risks with a caesarean section, well you know, I’ll do whatever’. And he said there’s no facts to say that one way is better than the other way, he said, so we’ll just, do it as it is. Also before I fell pregnant, I saw a liver specialist in Queensland just to talk about the risks of passing it on to the child, and he was very blasé and said, ‘well you know, six per cent. Sort of, you make the decision’. So there was nothing I could do to change the percentages. Kate

This is all you have to weigh up, I want more children and I will have more children but that’s why I have a healthy lifestyle, ‘cos I aim to use only natural alternatives [to the antiviral drugs] the less you can get it [hepatitis C viral load] down to nil then the chance of transmission [is reduced]. Very likely I won’t have a natural birth. I would like to have a caesarean section because again, that’s going to cut down [the risk of vertical transmission] because there’s not going to be the blood involved, as there would be in a natural birth. Jessica

There’s a lot of misinformation about, people don’t seem to know much about it [vertical transmission of hepatitis C] at all. Julie

The women who wanted more information on which to base their decision regarding vertical transmission wanted to have clinical tests to assess their risk of transmitting the virus to their baby. Jessica had read that women with a lower viral load have a reduced chance of transmitting the virus to their baby and so she wanted to get tests done that would give her information on which to assess her chances of transmission. However, she was having some trouble getting the tests done, despite having requested them from her doctor.

This is the problem as well, they won’t let me have my viral load [test]. I have asked several times and it’s just not available for people with hepatitis C. If I was HIV and I want a viral load they say, ‘oh yes there you go,’ but they just don’t offer it to hepatitis C people. I don’t know why. Jessica
Many women also changed their lifestyle to reduce the risk of liver damage and the associated malaise, with the assumption that this may also reduce the risk of vertical transmission.

I spoke to him about the kid, I said both their father and I had it when I had them and I could see the similarities. I said, well you know [ex-husband] and I were pretty healthy. We didn’t drink and you and I don’t drink and it stands to reason … The lifestyle is pretty much, is better now than when I had them I was using [drugs] and stuff like that. *Veronica*

This desire to try to reduce the risk of vertical transmission was evident when the women related the risk of vertical transmission to the risks associated with childbearing whilst on methadone maintenance treatment. Overall, for those women on methadone maintenance, there was greater concern expressed regarding their methadone maintenance treatment than hepatitis C. They justified this based on their perception that they were able to do something about their methadone use, by reducing their dose or coming off it altogether, but felt powerless to change the risk of vertical transmission of hepatitis C.

Well methadone would be a big concern for me because I could do something about that, the hep C I can’t do much about. *Ellie*

Now that we sort of feel comfortable about all those answers [about the risk of vertical transmission] and know that there’s nothing you can really do, and nothing that’s really going to make it happen. But yeah, methadone withdrawal [by their baby] is a lot more of an issue to us and that’s for sure. *Dawn*
Misleading and inadequate information from doctors

Many women reported receiving insufficient information and counselling about vertical transmission of hepatitis C and this left them feeling confused and frightened.

It would be good to have more information, but it’s still very basic. I mean, I just looked over and they give you a thing on breastfeeding, that’s what I asked my doctor and then the really big question, will my child be born hepatitis C positive? Can I pass it on? No-one could tell me. Theresa

The doctor in Queensland was pretty knowledgeable and said, okay, these are the risks and, but I sort of, you’ve got to really gather the information before you get to the obstetrician, like from the GP and I think GPs don’t know a terrible lot, not at all. It’s more the basics, like I would know more about hepatitis C than a normal doctor, I’m sure. Kate

One of the women who worked for a drug use organisation believed that many people, particularly current injectors come away from their hepatitis C diagnosis believing they cannot have children, largely because they think they will give their baby hepatitis C. She reported that one possible reason for this is that women with hepatitis C assume that the doctor will take for granted that they would not consider having children because of their IDU, and so they do not approach the subject with the doctor for fear of being judged negatively. It might also be the case, she reported, that doctors do not address the issue with women who have hepatitis C and are injectors, because they assume that these women would not consider having children because of their drug use, or that they should not be encouraging these women to have children. And so both parties remain silent on the issue because of their assumptions about each other.
A lot of doctors don’t seem to want to talk to people about the things that are important to those people and because people who have hep C themselves are too nervous to bring up some issues because, to bring up stuff about having kids and stuff, they might think, oh, the doctors got [judgemental attitude towards injectors].

Another woman who also worked for a user support organisation made a similar statement:

People are very unclear about that [risk of vertical transmission], like a lot of people come in here and as soon as they have been to the doctor and they just assume they can't have kids. Like the other day [a couple] came in and, like just the look on their faces, and we told them that wasn’t the case [i.e. they could have children] and they just looked at each other and gave each other this big hug, like it was their whole life had just changed in an instant. They were so devastated after being to the doctor and they were just so happy that they realised that it [hepatitis C] wasn’t the end of the world so much and I think it’s very, it’s sad that a lot of people are going to go away and think that [they can’t have children because they have hepatitis C].

Some women reported being given misleading as well as inadequate information regarding childbearing and hepatitis C, usually by their doctor at the time of diagnosis. Some women were led to believe that they would not be able to have children because they have hepatitis C. Becky was told that because she has hepatitis C, she could not have children, because she would infect them with hepatitis C. Becky also believed she was going to die early because of hepatitis C, because the doctor did not counsel and reassure her that this was unlikely.

It’s hepatitis and you should forget having children’. First off I thought, first initial thought is okay, this is going to transfer to my baby straight away. So that is what I walked out of the door of the doctor’s office thinking. Becky

Becky received conflicting information from different doctors regarding vertical transmission of hepatitis C:
I still didn’t really know that I wasn’t going to die of it. But he [doctor] did tell me that you have probably got maybe at the most, a one in 10 chance of passing it on. And he was the only person that actually said to me [that I could still have children]. One doctor that has actually said to me, ‘it’s not right, because you could have a chance of anything happening to a baby, like anything else.’  

Becky

Even after finding out about the actual risks of vertical transmission, and that her prognosis was not so bad, Becky expressed concern about whether or not she should have children because she has hepatitis C.

I mean I still don’t know the answer to this. Because I don’t know whether it’s right to have kids or not because there is a chance [of vertical transmission].  

Becky

It may be possible that some doctors were practicing ‘defensive medicine’ and were providing advice to women that (they perceive) presents less risk of litigation for a child acquiring hepatitis C through vertical transmission after advising the mother that the risk is low. Douglas however, (1994) points out that it is not the role of the medical professional to provide directive advice, but to provide accurate information on which patients can base their own decision. Yet the women in this study reported that not only did they receive inaccurate or insufficient information, but they were in fact sometimes given strongly directive advice about their reproductive decisions in light of the risk of vertical transmission of hepatitis C.

Some women, however, did report that their doctors provided them with good information on childbearing and hepatitis C. These doctors were generally reported to have a particular interest in hepatitis C, and in Hannah’s case was actually on the Hepatitis C Council. Much
of the information Hannah received was in written form, and she was also referred to authoritative sources of information, such as the Hepatitis C Council.

She just hit me with all the books and then told me to [go away, read them and have a think about whether to have a baby or not]. She was really informative, said have a think about it [having a child] and then get in touch with the Hepatitis C Council, go up there and get all the pamphlets, or ring them up and they will send them to you. She had all the books ready for me, here take this and then she said when you’ve had a read of it, get in touch with them when you’re ready and talk to them. **Hannah**

It was not only women who were concerned about the risk of vertical transmission. Although men were not interviewed in this study, several women reported their partners to be very concerned about the risk of vertical transmission. In fact, several women reported their male partners to be far more concerned about the risk of vertical transmission, than were the women themselves.

I would like to have a child and I know that he [partner] has some serious reservations about the responsibilities. You know, whether it is right for us to have children. He says, you have no right to bring a child into the world who has hep C I say, well, a) there is a chance and b) so what. He has some serious questions. **Georgia**

My husband wasn’t very keen in the beginning, because of that [risk of vertical transmission], because he said, what if we have a child that has hep C? And I said, well what if we don’t? **Sarah**

Overall the perceived risk associated with vertical transmission was not, in itself, so high that it would prevent any of the women in this study from having children. However, when the risk of vertical transmission was combined with other risks associated with hepatitis C, as well as other factors that usually influence childbearing decisions (as discussed in chapter five), it has a compounding effect, which can contribute to decisions not to have children. The women reported the risk of vertical transmission to be considered in relation to several
other risks. Some of these risks are inherent in most childbearing decisions, such as financial security, or their relationship with their partner, regardless of whether or not they have hepatitis C, but these issues may be magnified because of the effects of hepatitis C. There are other hepatitis C related risks that are also taken into consideration. These other risks surrounding hepatitis C largely revolve around their own prognosis in two different ways. Firstly, will they be well enough, or even alive, to care for their children? Secondly, will their own health deteriorate through having children?

Theresa had decided not to have any children for several reasons. Her main reasons were related to her concerns for her future health relating to hepatitis C. She was worried that she might endanger her own health by having a child because of the physical demands of childbearing and motherhood exacerbated by her fragile hepatitis C related health. She was also concerned that if she had a child and she did become sick from hepatitis C, then she would not be able to sufficiently care for her child. Theresa had considered the risk of vertical transmission and remained frustrated about the lack of information on associated risk factors. However, she considered the risks associated with her own hepatitis C related health to be far greater.

Lack of information. [There’s nothing] to be able to say [whether or not] I’d have a problematic baby, and I could suffer a bit of a relapse [of severe hepatitis C symptoms] or exhaustion. It would make it very difficult for me, so yes, the physical thing of labour and the specific, the whole scenario. I found this lack of information quite alarming. There probably might be a little bit more information but it was the final straw, you know. It [the uncertain physical effects of childbearing and motherhood] was too big a hurdle to overcome physically. I think it would be pretty tough going without extensively having family support. *Theresa*
What is at risk?

Many women focussed on the odds of vertical transmission occurring and whether these odds were acceptable. However, in any assessment of risk, it is necessary to consider what is being risked as well as the odds of a particular outcome. Very few women made reference to the implications of their child contracting hepatitis C from them, through vertical or household transmission. They appeared to neglect an essential component of any risk assessment; what is actually being risked? This is likely because it is the odds of vertical transmission occurring that are what the medical professionals discuss and focus upon, rather than the consequences and meanings of childhood hepatitis C infection. None of the women mentioned possible birth complications, or low birth weight, or other biological problems that might be associated with vertical transmission of hepatitis C. These issues were only considered in terms of the effects of drug use during pregnancy. Only a couple of women mentioned the social impact that hepatitis C would have for a child growing up. This concern about the social aspects of the virus may result form their own experiences, in which the social problems have been worse than the physiological symptoms.

It [her biggest concern about hepatitis C] would definitely be to do with passing it on to my baby, and also her having to deal with growing up, and having to worry about her passing it on to anyone. Abigail

The only thing that worries me about her getting it, is when she turns fourteen and she’s [existing child] getting into, starting to like boys and you know, starting to become mature, is whether she’s going to get sick from it. Because they say it takes, you know, seven, 14 years before you start feeling the effects of it. I thought well that’s really going to be bad if she gets sick when she’s that old, you know. I mean it’s bad if she gets sick at any point, but you know what I mean, I just thought it was… Dawn
Gemma’s child tested negative for hepatitis C at age two, and so is assumed to not have contracted hepatitis C from Gemma. However, Gemma still had some concerns about the potential impact of hepatitis C on her daughter, in case she had in fact contracted hepatitis C from her.

I worry that if she has hep C, like when she goes to school, like how hard is it going to be for her to make friends? *Gemma*

Fiona reported the risk of vertical transmission to have contributed to her decision to terminate a pregnancy recently. However, Fiona indicated that she was not fully aware of the effects that hepatitis C would have upon her child.

I was very scared of having the hep C and how it would affect the child. I would have been thinking, like, how is this going to affect my baby? *Fiona*

Unlike the other women, Dawn made a clear reference to the fact that, although it would be a problem if their child had hepatitis C, the child would unlikely be very sick or die (as a child) as a result (Lacaille, 2002; Rojahn and Wathne, 2002; Rouassant S, 2002; Schwimmer and Balistreri, 2000). This impacted on Dawn and her husband’s risk assessment of vertical transmission of hepatitis C and influenced their childbearing decision.

I think if they had said ‘oh yes, she’s definitely going to get it,’ and maybe there was some other consequence because she was young, but yeah, by the time she’s fourteen, she’s going to be bedridden with it, that might have a big effect on whether, you know, that probably would have had a big effect on us. But it’s not like that so you don’t have to worry about it. But if it was, of course it would have made a difference, for sure. *Dawn*

Some women believed that hepatitis C would present serious, and potentially fatal health problems if their children acquired it from them. As demonstrated earlier in the thesis, this
is not usually the case. The women assumed childhood hepatitis C to be similar to adult hepatitis C, or that vertical transmission would have unbearable consequences, but did not specify what those consequences would be. Georgia reported her partner’s fears to be great and although she did not consider them to be as serious as he did, she did consider the issues he raised to be important. Most of Georgia’s partner’s reservations about childbearing focussed on the effects that hepatitis C would have on their child. However, it is not clear whether or not he or she had any understanding of the effects of childhood hepatitis C, as opposed to the way hepatitis C affects adults.

He said that in this day and age there is enough to contend with without being born with a disease as well. He would be saying, look, the poor kid is going to bloody inherit some sort of a defective gene, they are going to maybe be born with hep C because these geriatric parents, and the poor bloody kid you know, and you want to have a kid like, you know, what are you wishing on this poor child. Georgia

**Blame and guilt**

It seems that the issue of blame and guilt was considered a significant, if not major, risk. That is, by having a child they were risking being blamed or feeling guilty for transmitting hepatitis C to that child. They reported feeling guilty for putting their children at risk of the hepatitis C virus, and that they greatly feared the guilt that they would feel if their child did contract hepatitis C from them. They were risking being blamed for harming their child. In contemporary society, it is a mother’s responsibility to protect her children from any harm and discomfort (Petersen and Lupton, 1996)\(^{32}\), before and after birth. Even if the child does not acquire hepatitis C from the mother, in presenting the risk of hepatitis C to their child, the woman who knows she has hepatitis C and has children breaks one of the ‘rules’

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\(^{32}\) See chapter 3 for further discussion of ideology of motherhood and mothers' responsibilities.
of this ideology. Consequently, she experienced guilt from exposing the baby to this risk, as well as risking the blame and grief involved with the possibility of vertical transmission occurring. However, the degree to which any risk to a child is acceptable is not solely dependent upon the statistical risk of a negative outcome occurring, nor on what exactly is being risked. It is in fact dependent on the social values attributed to what is being risked, by whom and for what purpose. Women with hepatitis C are highly stigmatised (Gifford et al., 2003; Hopwood and Southgate, 2003), and as such are socially devalued. Because of the association between their hepatitis C and IDU, they are also assumed to become neglectful or abusive mothers (in addition to being bad mothers for exposing their babies to the risk of vertical transmission), as female drug users are often assumed to be. Consequently, if hepatitis C were not so stigmatised, there might be a greater acceptance of the risk of vertical transmission for women living with hepatitis C.

In relation to other health problems among the general population, it is useful to look at testing for birth defects during pregnancy. Pregnant women in industrialised societies are routinely offered antenatal screening for conditions such as Down’s Syndrome, spina bifida and other birth defects. These routine tests are not diagnostic, rather, they identify which women are most at risk and who should be offered (and sometimes encouraged to undergo) more invasive diagnostic tests such as amniocentesis or chorionic villus sampling (CVS) in order to determine whether or not their babies are likely to be born with these serious (and some less serious) conditions. Those identified as being at greater risk of bearing children with these conditions, through screening tests and/or having other risk factors, such as being over 35 years of age or already having a child who has an inherited disorder, are offered diagnostic tests.

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33 Birth defects are considered to be ‘an abnormality of structure, function or metabolism present at birth that results in physical or mental disability, or is fatal’ (The March of Dimes, 2003).
There are also some risks associated with these invasive diagnostic tests to consider in this risk assessment. Amniocentesis carries an added risk of about one per cent of miscarriage, but repeat procedures carry a much greater risk. Amniocentesis is also associated with increased postural orthopaedic deformities and some minimal maternal risks (Harper, 1998). The risk of a child being born with any kind of congenital deformity (of highly variable severity) is about one in 30 (Harper, 1998). However the varying types and severity of these deformities will strongly influence the ways in, and degree to which the child or its family will be affected.

The severity of birth defects varies greatly, some may greatly impact on the quality of life or life expectancy of the child and others may not have a large impact at all. Given the eager testing of pregnant women for these other birth defects, it seems that these risks are perceived to be high. When comparing the risks associated with vertical transmission of hepatitis C, as with these other conditions, we must look beyond the risk of transmission to exactly what is being risked. Children with other ‘defects’ they were born with may experience enormous health related problems, even death, as well as possibly having a huge impact on their family’s life. The effects of hepatitis C on children are not yet clear as research is in its infancy. However, based on existing studies, it seems that children tend to fare better than adults with hepatitis C, and many are asymptomatic, as discussed in chapter one.

The risk of bearing a child with a ‘defect’ has not prevented people from having children. Attempts to minimise these risks are substantial though, through widespread use of prenatal screening and diagnostic tests. The woman (or couple) who decides to not have the diagnostic tests and to continue the pregnancy may encounter medical and public scrutiny in a similar way that a woman with hepatitis C could. Drawing upon examples of
British Pakistani couples, Shaw (2000) demonstrates that perceptions about risk surrounding prenatal testing are culturally determined, and as such this scrutiny and possible criticism is also shaped by cultural values. Shaw (2000) found that even with the knowledge that their babies were at very high risk of being born with a severe, and usually fatal condition, Pakistani couples refused antenatal testing. This was because they would not terminate the pregnancy for religious reasons even if the test showed that the baby would be born with such a condition. Similarly, Hill (1994) reported that black American women of low SES who were identified as being at very high risk of having a baby with sickle cell disease, a serious and debilitating condition, also rejected confirmatory testing. As with the British Pakistani couples, at first these decisions may appear irrational. When cultural and social conditions are taken into consideration, however, these decisions are quite logical.

Judgements about whether or not a pregnancy should be continued, or whether or not a woman should have children at all if there is a risk of the child being born less than medically perfect, are made on assumed quality of life of children and adults living with these conditions. The effects of hepatitis C on children are not yet fully delineated, and as such it is extremely difficult to make any judgement about whether or not it is morally right or wrong to have a child if that means exposing a child to the risk of vertical transmission of hepatitis C.

The absence of screening and diagnostic tests for birth defects is unlikely to prevent people from childbearing. Unlike other conditions which may be detected during pregnancy, it is not yet possible to predict which women with hepatitis C are more likely to transmit the virus to their babies, therefore accurate risk assessment and diagnosis is impossible. Until more accurate testing and prediction relating to vertical transmission is available, women
with hepatitis C should not be expected to avoid childbearing, just as the general population would not be expected to in the absence of testing for other conditions.

Both current and past injectors and those who had never injected described feelings of guilt about putting their baby at risk of vertical transmission of hepatitis C, and that they greatly feared the guilt that would accompany their child being diagnosed with hepatitis C. Most women described a moral component in their childbearing decisions regarding vertical transmission of hepatitis C. They questioned whether or not it was ‘right’ for a woman who has hepatitis C to have children because of the risk of vertical transmission.

Risk is closely associated with immorality, and the people living with the risk are often blamed for their own misfortune because of immoral behaviour (Lupton, 1993). For example, gay men are often held to blame for acquiring HIV/AIDS through homosexual sex (Brown, 2000; Glick Schiller et al., 1994); and prostitutes responsible for the sexually transmitted infections and violence they experience (Day, 2000). Because women with hepatitis C are assumed to have (and the majority have) acquired hepatitis C though IDU, they are perceived to be responsible for their condition and the risks and social costs it presents to others, especially their children.

A similar sense of guilt was described by participants regarding the risk of their babies experiencing withdrawal symptoms because of their drug use or methadone treatment whilst pregnant. This is because they (and others) perceive they have some control over their drug use, and so are to blame for their child being put at this risk. If their children do experience withdrawal symptoms, their sense of guilt is magnified. They are perceived, by the lay public and themselves, to put themselves at risk through IDU, which is behaviour ‘choice’, and therefore preventable.
A lot of women do stop using drugs, just be on their methadone [when pregnant]. And over-compensate, you know, a lot of women out there really over-compensate when they have children. Especially the guilt that is put on them by the hospital, when they are giving birth. They need to prove that they are as good or better mother than other people. *Sally*

Several women reported that they felt guilty because they have hepatitis C and the problems and risks this creates for other people, particularly their children. Certainly the women who had never injected drugs also had some sense of guilt surrounding hepatitis C and childbearing. These women also reported feeling guilty and fearing further guilt associated with having children. For these women, their guilt was focussed on their decision to have a baby and in doing so, placing their baby at risk of vertical transmission of hepatitis C, and that their own health may limit their abilities to care for their children. For the women who were current or past injectors, however, this sense of guilt reached deeper into their social identity.

**Breastfeeding**

Many of the women interviewed were concerned about the risk of vertical transmission of hepatitis C through breastfeeding. Despite current guidelines advising that women with hepatitis C should not be discouraged from breastfeeding, some women reported being advised not to breastfeed by medical professionals involved in their maternity care. Based on this advice, some of these women had not breastfed their babies. Not breastfeeding can impact negatively on the health of both mother and child as well as denying both parties the emotional bond associated with breastfeeding (Palmer, 1998).

*All I know is that I could probably pass it on to her. She had cows milk, it was easier. *Gemma*
I would be scared of breastfeeding and that they would catch it. I don’t know what the risks are. Jean

The tablets that I actually took in hospital to stop my breast milk when I gave birth to [son] because I was worried he would get hepatitis C from the breast milk. Kate

Sarah asked her obstetrician if she could breastfeed and was told that she could but he also implied there was a risk of vertical transmission of hepatitis C. The way this was presented to Sarah implied that if she did breastfeed and her child contracted hepatitis C, she would be to blame. Sarah decided not to breastfeed because she feared this blame and the guilt that would ensue. Her fear of this happening appears to be greater than the many infant health problems that are associated with not breastfeeding (Palmer, 1998).

He [obstetrician] was the one who asked me not to breastfeed. He didn’t advise me not to breastfeed, he just said, ‘go ahead if you want to breastfeed, but if your child is infected, you’ll never know whether you could have stopped it if you didn’t breastfeed.’ Sarah

Two women did not breastfeed because they were advised not to by their obstetricians and other medical professionals because they have hepatitis C. Both of them reported that they attributed becoming pregnant again very soon after giving birth to not breastfeeding. Both women carried the subsequent unplanned pregnancies to term and as a result had two young children very close together. It should be noted, however, that lactational amenorrhea is not recommended as a reliable method of family planning in industrialised societies, especially as so many women now do not breastfeed (Palmer, 1998).

Not all women with children had been advised that they should not breastfeed because they have hepatitis C. In particular, those diagnosed with hepatitis C recently, such as Abigail, were advised that they should still breastfeed.
They just always told me that I could. Like the first thing that they made sure that I knew, when I was like, when I had that dreadful look in my face when I found out. It was like ‘don’t worry, you can still breastfeed,’ and I went, that’s good. Abigail

Some women related the issues of breastfeeding when hepatitis C positive, with breastfeeding whilst on methadone treatment. As with hepatitis C, Veronica believed that it is the stigma associated with being a mother on methadone that influences people’s perception of the risks involved, just as the stigma surrounding hepatitis C appears to influence perceptions of the risk acceptability of vertical transmission. That is, although medical evidence indicates that most women with hepatitis C should breastfeed, the risk of vertical transmission of hepatitis C through doing so socially unacceptable. Ironically, the risks associated with not breastfeeding are deemed more acceptable, as Veronica demonstrated. Veronica was challenged about breastfeeding her child when she was on methadone by medical professionals and acquaintances. She had consulted several medical professionals who informed her that this is not damaging to her baby and in fact may be beneficial because it could in fact help prevent the baby from experiencing distressing withdrawal symptoms from the mother’s methadone. This also indicates that breastfeeding remains undervalued in contemporary western society (Palmer, 1998).

It comes into it with methadone. I think they said it’s even less through milk than through blood but there was no advice against it. The reason they had two schools of thought; there are some which say don’t breastfeed and some which say, definitely do [breastfeed], because it supplements the [methadone] babies are no longer getting in the womb and as I come down [on methadone dose]. Actually, I used to get comments from people, they used to say, ‘ooh you must have such good milk, what a thriving baby.’ They used to complain about me breastfeeding while I was on methadone. People do, they have a stigma about it [breastfeeding whilst on methadone]. And one of the girls I know recently was concerned that my baby was being hurt because I was on methadone, even though I tried to explain to her everything, she said, ‘I don’t know, it doesn’t make sense to me, I think it’s got to
Summary: The risk of vertical transmission of hepatitis C affects childbearing decisions

For some women, vertical transmission was the topic of long and serious consideration, and some of these women had not reached a conclusion on how they felt about it. For other women, however, the risk of vertical transmission was considered, and dismissed as a factor in their childbearing decisions once they obtained information that led them to be satisfied that the risk was sufficiently low. A small minority of women had not really considered the risk of vertical transmission, either because it had not occurred to them, did not consider it to be important, or because they had not approached the subject as they had not considered having children.

There was a great deal of variation in the perceived degree of risk associated with vertical transmission of hepatitis C. For a minority of women it was a major factor in their childbearing decisions, particularly when considered in relation to other uncertainties and problems posed by hepatitis C, in addition to all the factors that influence childbearing decisions in general. For other women, it represented a very small risk, and was one which they perceived they could do little to change, and so did not consider it to be worthy of great concern.

Illicit drug use, particularly injecting, has been associated with risk-taking personalities (Katz, Fromme and D'Amico, 2000; O'Brien, 2003). That is, some people such as injectors, are more likely to engage in risky activities, because of their personality traits (Knowles, Cutter, Walsh and Casey, 1973). Most of the women in this study were current or past...
injectors. It may be the case that the risks associated with childbearing and hepatitis C are perceived and dealt with differently by women with hepatitis C (compared with the general population) because they have a risk-taking personality. Another school of thought dating back as far as the 1960s (Slovic, 1962) claimed that risk taking is determined more by the situation than by the individual personality. Other approaches to the study of risk related behaviour also indicate that behaviours considered to be of high risk, such as sharing injecting equipment, are determined according to a range of social and environmental factors (Loxley, 1998; Plumridge and Chetwynd, 1999; Rhodes, 1997; Rhodes et al., 2003; Southgate et al., 2003). There are also reports of women injectors who explain their drug use through having an ‘addictive personality’ (Plumridge and Chetwynd, 1999), rather than a ‘risk-taking personality’; indicating that they feel they lack agency. Men in the same study explained their drug taking in very different terms.

The social stigma associated with hepatitis C and IDU influences assessments of the risks associated with vertical transmission because stigma influences the social acceptability of risks. All risks are socially constructed and the acceptability of risks is determined by social value (Douglas, 1985; Douglas, 1994; Lupton, 1993; Lupton, 1995; Lupton, 1999). Hepatitis C is doubly stigmatised, because it is infectious and closely associated with IDU (Anti-Discrimination Board of New South Wales, 2001; Armishaw and Davis, 2002; Gifford et al., 2003; Hopwood and Southgate, 2003). The risks associated with vertical transmission of hepatitis C are magnified through the lens of the social stigma associated with the virus.

The women described feeling very fearful of the guilt that they expected would be placed on them if their child contracted hepatitis C from them. This guilt is perceived to be so great because of the social stigma of hepatitis C. Because hepatitis C is associated with deviant behaviour, there is an implied element of blame involved the in participant’s
infection, and the risks they pose to others because of it. Within the ideology of motherhood as described in chapter five, mothers are expected to put the wellbeing of their children first and are almost totally responsible for their wellbeing. When a woman who has hepatitis C has a child, she is perceived to be placing her child at risk, thereby in conflict with motherhood ideology. As such, this can be interpreted to make her a bad mother, and to have failed as a woman, as found among women with HIV/AIDS (Lawless et al., 1996).

**Hepatitis C related physical and emotional health impacts on childbearing decisions**

The women reported their current physical and emotional hepatitis C related health, as well as fears for their future hepatitis C related health, to impact on their childbearing decisions.

Women who were experiencing physical or emotional problems because of their hepatitis C at the time of interview reported this to have an impact on their childbearing decisions. Fiona reported hepatitis C to affect her overall sense of wellbeing that goes beyond physical symptoms, and for this to have impacted on her recent decision to terminate her pregnancy. The physical and emotional effects of living with hepatitis C, combined with other considerations, such as the risk of vertical transmission and her poor financial situation led Fiona to her decision to terminate a pregnancy a few months prior to the interview.

I feel like maybe it [hepatitis C related health] affected my decisions [about her pregnancy] in the way, not just in the way that I would have been thinking like, how is this going to affect my baby? But because it would make me more emotionally unstable and because of how it affects you holistically, the rest of your body, by mainly making you a bit down or a bit negative. Once you feel down you can start feeling negative. Would I be able to
cope more emotionally, yeah but I was thinking I haven’t even healed my body and I’m trying to get rid of this disease and stuff. Would I be able to cope financially? Would my body be able to cope when I get too fatigued? Emotionally, would I be able to have this child in my life? Fiona

Although Fiona was the only woman to describe the emotional and holistic effects of hepatitis C in great detail, and directly relate it to her childbearing decisions, other women did report their emotional health to be a concern, and for hepatitis C to worsen their emotional health, through the physical symptoms it produces and the social problems it created through social stigma, which are discussed separately in chapter eight.

I know when I am having a bout of it [hepatitis C] flaring up, it is very uncomfortable and I do get depressed. Sharon

I’m a pretty easy-going person, but I get easily agitated when I am feeling that way. Theresa

Justine reported that she would like to have children, but her physical, and to some extent, her mental health was the main reason she was delaying childbearing.

If I feel, like after some time, I feel like my health is fairly stable that it’s not getting worse, or that it is actually improving, my symptoms are improving [then I will have a child]. Justine

Whilst severe emotional problems exacerbated or caused by hepatitis C may not be very common, it is nevertheless a salient issue. It can have far-reaching implications, and as Fiona demonstrated, contribute towards the decision to terminate a pregnancy.

Whilst few women reported that their current physical or emotional health was preventing them from having children, several women highlighted that hepatitis C caused them few problems in regards to childbearing, because they were asymptomatic. This implies that for
women who are experiencing physical and/or emotional problems relating to their hepatitis C, this may influence their childbearing decisions. Hepatitis C has the potential to impact upon the childbearing decisions of women who are currently asymptomatic and emotionally healthy because of the chronic and fluctuating nature of the virus. Hepatitis C can represent the threat of future poor physical and emotional health.

I think you know, as long as you are well, if you are at that stage where you are well and you don’t think you have any symptoms, I think you can manage it [motherhood] and kind of get on with your life and roll with the moment. Janice

For most women, however, it was not their current symptoms but the fear of future poor hepatitis C related health, and for some women, early death, that was reported to be a major concern in relation to childbearing decisions. Many expressed concern that because they have hepatitis C, they may not be well enough in the future to be able to sufficiently care for their children, and under such circumstances, had doubts about the morality of having children. That is, they expressed uncertainty about whether it is fair to their children and partner to have children if they know there is an increased risk that they may not be able to care for them in the future because they have hepatitis C. Most women were aware of the natural history of hepatitis C. However, this was not very helpful to many women when assessing whether they would become sick or die from hepatitis C.

Like the risks of vertical transmission, there was little information available to the women to advise them on the odds of becoming very sick or dying from hepatitis C. They felt that, based on what they knew about their prognosis (which was usually very little, even for those who had seen a liver specialist), they were unable to make an informed decision about having children in relation to their hepatitis C related health. Although only a small proportion of people living with hepatitis C develop serious liver problems, and very few
die from hepatitis C, this was a real concern for the women, particularly in relation to motherhood. Even for those women who perceived their chances of becoming very sick to be low, this was a source of great anxiety.

As reported in the previous chapter, many women reported making changes to their lifestyle after being diagnosed with hepatitis C. By making these changes, the women perceived that they were improving their prognosis, and as such it was less of a risk to have children. In making these changes they perceived they were becoming ‘good’ or ‘better’ women, which would in turn make them better mothers. As better mothers, they would also be ‘better’ women. The women considered their ‘unhealthy’ and ‘immoral’ lifestyles inappropriate for motherhood, and by changing these, they were working towards the development of a new identity that is more appropriate to motherhood, as well as the perceived benefit of reducing the risk of becoming very sick, which would limit their abilities as a mother.

Some women reported that they wanted to know more about the current state of their liver, that is, the degree to which, if any, it has been damaged by hepatitis C, so that they would have more information on which to base their decisions on whether to have more children. Each of these women had requested tests from their doctor, but been refused for different reasons. Kate requested a biopsy be performed on her liver, but because all the other tests she has had over a period of time have all indicated that her liver is functioning well, her liver specialist advised her that it was unnecessary. Kate wanted this sometimes painful and occasionally risky procedure (Janes and Lindor, 1993) performed to provide her with more information on which to base her decision whether or not to have another child. She perceived the risk of her developing severe symptoms or dying from hepatitis C whilst
her children were still young to be great, and as such she wanted more information on which to base her risk assessment.

I haven’t had a biopsy at all. I have blood tests every two months, liver function tests. And they’ve all come back normal so far. I have another one in two weeks time and that will be my, the liver specialist wanted to, over a six month period do every second month. And she said usually, in a six-month period, the liver function tests will come back abnormal. And then we can do a biopsy to see how badly damaged the liver is. Because I told her that I want to have another child, but am worried about having another child if my liver was badly damaged. Because I don’t want to die in 10 years time with three kids. I’ve got two now, you know. And she said, ‘well, the only way you can have a biopsy is to have the like, liver function tests be abnormal.’ Kate

Kate eventually convinced her doctor to refer her for a biopsy because she was trying to decide whether to have another child or not.\textsuperscript{34} After reconsidering the liver specialist’s advice, however, Kate decided not to have a biopsy performed, and instead chose to focus on lifestyle changes that might improve her prognosis.

I’m all confused because I don’t know how badly damaged the liver is. And she said well, ‘I guess we could do one if you really wanted to, I can see your predicament.’ And then I said, oh, forget it, I won’t worry about it. So what do you do? You just try, I’m trying to live um, a healthy lifestyle as I can, and before I started seeing the liver specialist, I didn’t realise that drinking alcohol had such a bad effect on your liver. Kate

Theresa was concerned about her future hepatitis C related health, especially so if she chose to have children. Theresa’s case demonstrates many of the considerations facing women with hepatitis C, although there are a number of factors that influence Theresa’s perspective, which may not be the case for many women. Theresa has decided to remain

\textsuperscript{34} Liver biopsy is covered under the Medical Benefits Schedule, but requires a referral from a gastroenterologist (Commonwealth of Australia and Australian Institute for Primary Care, 2001).
childless because she fears that having children will endanger her already fragile hepatitis C related health, and that this would be unfair to the child that she might have, and to her partner who would have to shoulder much of the responsibility of caring for the child. Theresa reported she would need to have a lot of practical and emotional support to be able to have and care for a child. However, this support is not available to her, and the responsibility for the care of the child would be shared between her and her partner only.

Theresa reported that if she were younger, she might have come to a different decision about having children. She had hepatitis C for over 20 years, and had experienced moderate, though manageable, symptoms, as well as having had both hepatitis A and B in the past from which she experienced severe symptoms. Theresa believed that because of the degenerative nature of hepatitis C, combined with the usual effects of aging on the body, the risks to her health posed by childbearing and motherhood are too great, considering that her desire for a child is not great. Additionally, Theresa reported having witnessed friends and family suffer greatly from hepatitis related disease including her mother dying from liver cancer, all adding fuel to her fears for her health.

Theresa had discussed her childbearing decision in relation to her hepatitis C at great length with her doctor with whom Theresa had a very good, long term relationship. Theresa reported that her hepatitis C symptoms were usually manageable and overall, she was able to live the way she wants to and did the things she wanted to. However, she perceived that the threat that childbearing would pose to her health would also pose threats to other aspects of her life, including her relationship with her partner. Several of Theresa’s reasons for deciding not to have a child, such as the threat it would present to her relationship with her partner and her lifestyle, were similar to those cited by childfree women in the general
population (see chapter five). However, in Theresa’s case, these factors only became important because she had hepatitis C.

She [her doctor] said it would be possible [to have children], but, you know, she’s a lovely doctor. She said, ‘look, unless you really, really want one, you know, you’ll have to do everything for yourself.’ Like it’s just me and my partner, it’s not like, you know. I mean my mother was 40 when she had me. And my partner’s mother, is in her 70s. It’s not like, you come home with a new born baby and your mum comes and stays with you for the first two weeks. It’s just the two of us, with one going out to work. And with that scenario, which she [her doctor] understood quite well, it would be too hard. Because you would either suffer physically or break down what is a very good relationship. And I don’t feel that strongly, to have our own children. I’d love to finish working, I’d love to work part time now, so that I could do things in case I’m not going to be around in another 15 years time. I do think like that. I think I’m probably a bit of a pessimist at heart but, you know, people say, ‘oh I’m going to live to 70, 80, 90. I don’t ever think like that. Theresa

Other women also described fearing the effects of having children, or more children, on their hepatitis C related health.

As I got older, being tired and not being able to keep up with the management of a child and if I had to work. Just that, money probably and health [would be major concerns]. Ellie

It’s hard enough looking after the two [children]. It’s too daunting to even think about, so, am I being stupid to think about having a third child? Am I being selfish? I’ve thought about that a lot, and I’m thinking, well I’ve been well up till now and I’m, if I do something positive about not drinking too much, well like maybe I’ll be well for another 20 years. Kate

Kelly had two children at the time of interview, but said she would consider having another child in the future. However, her concerns related to the children she already had and how they would be affected by another sibling through the effects of this on her health.
Summary: Physical and emotional effects of hepatitis C affect childbearing decisions

Physical and emotional hepatitis C related health problems were reported to influence childbearing decisions by a small number of women but very few women reported experiencing physical or emotional hepatitis C related health problems at the time of interview. Other women reported that their hepatitis C related health did not affect their childbearing decisions, and that this is because they did not experience current physical or emotional hepatitis C related health problems. It is important to note, however, that many women reported experiencing other emotional health problems not directly related to their hepatitis C, but possibly worsened by it. Several women reported experiencing being depressed, some seriously so, for extended periods of time. In fact, some women reported having attempted suicide at least once.

Fears for future hepatitis C related health problems, particularly physical health problems, were reported to be a significant, and for some women, a major consideration, in their childbearing decisions. These fears, of varying levels, were reported by the majority of the women. They were concerned about their own health; the effects that having children, or more children would have on their hepatitis C related health, through the physical and emotional demands of childbearing and motherhood. Many women reported feeling concerned about the wellbeing of their existing and future children if they were to become sick or even die from hepatitis, and the consequences of this for their partners.
The uncertainty and lack of information surrounding hepatitis C prognoses was reported to make childbearing decisions very difficult. The women felt they were taking greater risks because of a lack of information on which to base their decisions. The women reported that they were unsure whether it was morally acceptable to have children while they had hepatitis C positive, because of the risks this poses to their own health and the wellbeing of their existing and future children, as well as their partners.

**Childbearing can conflict with treatment for hepatitis C**

Several women reported that childbearing, particularly the timing, was weighed against treatment for hepatitis C (treatment being antiviral treatment using Interferon alone or in combination with Ribavirin). While it is possible to estimate the likelihood of treatment clearing the infection, ‘it is not known [before treatment commencement] if treatment will reduce their chances of becoming sick or dying from hepatitis C’ (Edlin, 2002: pS211). Some women faced the decision about which they should do first; hepatitis C treatment or having children. If they have treatment for their hepatitis C first, they perceived this would reduce the risk of vertical transmission, as well as improve their own prognosis. However, this may result in them leaving it too late to start having children because of their age or other factors. By the time they had recovered from the treatment, they may be too old to start having children, or other factors might have changed that would make having children more difficult or impossible. Alternatively, if they have children before hepatitis C treatment, it may be that they develop further liver damage before they are able to begin treatment. Additionally, this may cause problems in caring for their children. There is also a risk that the treatment will not make the desired improvements to their health or
prognosis and they may have sacrificed having children for little, or no gain. Additionally, the side effects associated with Interferon treatment can be debilitating, and as such, treatment has several costs which must be weighed against the benefits. Naturally, this issue was of greater concern to the older women in the sample.

For some women, such as Becky, the decision focussed upon timing of childbearing. At the time of interview, Becky was facing a dilemma; should she have treatment for her hepatitis C before having a child, or should she have a child and then reconsider treatment later? As she was in her mid-20s, Becky was not so constrained by age as other women in the sample facing a similar decision. Becky had experienced fertility problems, which she attributes to her use of hormonal contraceptives over several years. Becky reported that she would prefer to complete hepatitis C treatment before having children, but she was hesitant to do so as she feared that the contraceptive use that is required during treatment for hepatitis C will exacerbate her fertility problems, and that she may never be able to have children as a result. Becky reported being very anxious about this decision, as she would prefer to complete treatment for hepatitis C first in order to improve her own prognosis, which would benefit both herself and her child, as well as reduce the risk of vertical transmission. However, she did not want to risk permanent infertility for these benefits.

One of the conditions of having the treatment is that you are on two forms of contraception. Now I don’t want to go on contraception because I know I can’t get pregnant anyway, and I have been trying to get pregnant before. Now here is the choice, I

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35 A sustained virological response (i.e. successful treatment) to combination therapy (Interferon and Ribavirin) is found in approximately 41 per cent of patients, but this varies according to the genotype of hepatitis C, the patient’s viral load and the existence of cirrhosis (Commonwealth of Australia and Australian Institute for Primary Care, 2001).

36 It is a requirement of heterosexual men and women of reproductive age to use adequate contraception during, and for up to six months after treatment because of the risk of birth defects from the Ribavirin now commonly used in hepatitis C treatment. Both the person undergoing treatment for hepatitis C and their partner must use a form of contraception, that is, two different forms of contraception, one for each partner (Commonwealth of Australia and Australian Institute for Primary Care, 2001).
am 25 now. I try and get fixed up fertility wise and I have a baby and I take the chance all right, and I take the chance that there might be a five per cent or whatever. Now this is all I know, this is why more information is needed. I can’t make this decision. I have just been on fertility treatment for the last three and a half years, I don’t want contraception. How the hell are we going to get over that one? Maybe I should really say okay, go on contraception. Maybe that will end my chances [of having a baby]. What should I do? Should I do the contraception? Do the treatment? I said, maybe a coil, but the doctor said to me you can get Chlamydia, they don’t give you a coil if you have had a baby. So maybe a diaphragm but I just have a feeling that the condition of that treatment is going to be the pill. Now I will not ever have a chance to have a baby with hepatitis [through vertical transmission] if I can go out there and have some treatment for my, even if it doesn’t cure me completely, it could make me test negative, which means then that I have real much, much less chance of passing it on, if I am testing negative [i.e. if she manages to clear the virus through treatment]. Becky

Becky had been discussing having treatment with her liver specialist and expected to have a biopsy soon which she was very anxious about. The biopsy was to be performed to determine, medically, whether or not she should have treatment based on her need and whether she is likely to respond well.

I am scared to death. That’s a very serious start is a liver biopsy and everything I have heard about liver biopsies has scared the holy crap out of me. Becky

For some women, who were older, this was a decision of whether to have children or not, as if they selected to undergo treatment, they perceived that the duration of the treatment and allowing sufficient time for recovery afterwards, would mean they are ‘too old’ to begin childbearing. ‘Too old’ meaning that childbearing would be problematic in a biological sense, in that they may not be able to conceive any more, as well as being physically strong enough to bear and look after children.
Hannah had decided that she did not want to start Interferon treatment yet, that she wanted to have a baby instead and suspected she was pregnant at the time of interview. Despite being advised that she had a very good chance of success if she had treatment for hepatitis C, Hannah decided to delay treatment because she did not experience any severe hepatitis C symptoms. Hannah perceived her symptoms to be an indicator of how badly affected she was by hepatitis C, and to what degree she needed treatment. Based upon this assessment, Hannah’s current health problems were not sufficient to warrant the unpleasant and sometimes debilitating side effects of the treatments currently available. Given that she is in her late 30s, Hannah she feared that if she began treatment now, which would take approximately 12 months, she would then need more time afterwards for her body to recover, that this may leave it too late to start trying to have children. Hannah was fearful of living to regret not having had children and was eager to satisfy her husband’s desire for children. She reported that if she felt the need, or treatments had improved in several years, she would then re-consider hepatitis C treatment. Hannah perceived that after treatment and ‘getting rid of’ hepatitis C, she will be able to assume a different identity, an identity that is no longer shaped by her having hepatitis C, however, she is not willing to risk developing an identity of a permanently childless woman for this.

I just wish I was 10 years younger, I would have gone ahead with the treatment and sorted that out, no matter how sick. Professor, [doctor], had said that, in your case, he would pretty much put it down to 90 to 95 per cent that I would be off the hook after it [treatment]. But, he [doctor] said that it’s according to that most people of your level [of hepatitis C] have seemed to come out with none of it, it’s gone. So, yes I would have loved to have gone down that road but being 37, I turn 38 in November, then I thought six months of that treatment, that’s huge, and how’s my body going to recover from that and then go on to childbearing? So, I figured I’m in a healthy state today than I would be if I did that whole rigmarole, for my age. Just chance I suppose. When the time’s right I’d love to [have hepatitis C treatment]. Yeah, I’d love to. Just get rid of it, because I may have a different life again. 

_Hannah_
Approaching her 40s, Hannah believed she had to choose between children or hepatitis C treatment, for the time being at least. Although she may still have treatment in the future, she perceived it would be more difficult for her to postpone having children, than treatment. Age was reported to factor in their decision about whether or not to have treatment, which in turn was related to their decision of when, and if to have a child. However, having hepatitis C made this issue far more salient and of immediate concern.

I don’t know, like the whole thing was, do I do the treatment before I have children, knowing that I wasn’t sick? I suppose I’m taking a chance. I don’t know. I don’t know if it [having children before treatment] is the right way or the wrong way. Hannah

Linda was very keen to complete treatment for hepatitis C and come off methadone before having another child. Linda reported that her ability to perform regular daily activities was restricted by her hepatitis C symptoms, in combination with her drug dependence problems.

I want all the treatment over before I even consider having a child. Because if I get rid of it [hepatitis C], or get it so that it is in my system but dormant, then fine. Linda

Theresa had been advised not to have the treatment for hepatitis C by her sister who had recently been on Interferon treatment for another form of hepatitis. In particular, she was advised that undergoing treatment, as well as having children, was physically too demanding and should be avoided. In combination with a range of other hepatitis C related factors, this contributed to Theresa’s decision to remain childless.

And she’s [sister] had all the biopsies and [treatment]. She said ‘don’t have the treatment because it ravages you, it ravages your body.’ She had her last pregnancy at 36 and she says it’s hard work because she’s always very tired, and because of her diet. Theresa
**Summary: Hepatitis C treatments can conflict with childbearing**

For younger women, completing hepatitis C treatment prior to childbearing and it being successful has advantages. For older women with hepatitis C, however, the decision on the timing of hepatitis C treatment and childbearing may result in some women remaining childless. If they decide to complete hepatitis C treatment before childbearing, the duration of treatment and recovery time, as well as allowing time for conception to occur may result in her leaving it too late. Unfortunately, those women most in need of treatment for hepatitis C are those who have been living with the virus for longer, and so they are usually the older women. However, it is younger people who are most likely to respond well to treatment (Commonwealth of Australia and Australian Institute for Primary Care, 2001).

**Age and hepatitis C affect childbearing decisions**

Delaying childbearing to an older age, as is the trend in contemporary Australia (see chapter five, may not be an option for women with hepatitis C because the longer they have hepatitis C (and the older they become while they have hepatitis C) the more likely they are to develop liver damage and experience severe and debilitating symptoms, sometimes requiring liver transplantation and for a very small minority, death from hepatitis C.

Age was considered to be a major factor influencing childbearing decisions by all of the women interviewed. For several women, age was the most important single factor influencing their childbearing decisions. This is a factor incorporated into childbearing decisions of most women (Beckman, 1982; Robinson and Harbinson, 1980). Hepatitis C can be a degenerative disease that worsens over time, and so having hepatitis C increases the weighting given to age in childbearing decisions because having hepatitis C serves to
accelerate the transition to poor health and reduced functioning normally associated with the natural process of aging.

One of the most commonly reported symptoms of hepatitis C is lethargy (Commonwealth of Australia and Australian Institute for Primary Care, 2001). This symptom was perceived to be particularly challenging to the role of motherhood by the women in this sample. Within the contemporary social construction of motherhood, there remains great value placed upon ‘intensive mothering’ which is physically and mentally demanding (Gross, 1998; Hays, 1996) and lethargy poses challenges to women’s ability to provide ‘intensive mothering’.

Overall, the women wanted to have children before they faced the possibility of becoming very sick from hepatitis C. They were all aware that the possibility of becoming sick increases with age because the older they are the longer they will have been living with hepatitis C, and the more likely they are to experience the symptoms associated with liver damage. However, as previously highlighted, being aware of the natural history of hepatitis C, that is, assessing the likelihood of becoming very sick or dying from hepatitis C, does not make their risk assessment much easier as little is still known about the predictors of disease progression.

Age was directly related to concerns about physical health, particularly their future health. The women expressed concerns about their ability to cope with caring for their children if they became sick from hepatitis C. This is a responsibility they felt they must fulfil, and is an essential part of being a mother. While many mothers may share this concern, the threat that hepatitis C poses to their health meant this was of greater concern than would normally be the case in the general population. Several women reported that they felt it was
important to have children whilst still young, which in their opinion, was roughly below age 30. Karen had two dependent children and did not want any more because she felt that she was too old to have more children.

I’m 43, I don’t want any more. You know, you’ve got to have them in your early 20s. You have to have them in your early 20s, manage a career if you want it, and manage your lifestyle. Because when you get to my age, 43, your child is already 20. And you are at the age to appreciate life more, to get more out of life. Because at a younger age you don’t really appreciate anything as much as you do when you get older. So that’s why you have your children when you’re young, so you work, work, work, and then when they’ve grown up, and you’re 40-odd, then you can really enjoy life and you’re still young to do anything that you want to do. Karen

For some women, age was so important because of their hepatitis C and the way it affected their health over time. Theresa had decided to remain childless for several reasons associated with her hepatitis C status. She stated, however, that if she were facing the childbearing decision at a younger age, she would be far more likely to have a child, because her body would be more capable of dealing with the demands having children would make on her, and she would not have been living with hepatitis C for as long as she has.

Well I never felt a very strong urge [to have children] but then sort of mid-30s I thought, oh it’s going to happen. And then I got into a relationship at 40 and, just after my birthday I was with a man who wasn’t really interested in having children either. And then at the end of last year, I got into a bit of a panic and I said, it’s now or never. Maybe if I was 24 or something, and had that on my side. It actually became an issue for me at 40, to 41. Yeah, and financial and a lack of family support would be three. Theresa

Until recently, Sarah had planned to have more than one child. She recently gave birth to her only child, but reported that it would be very unlikely that she would have any more children, largely because of her age and the risks to her health presented by hepatitis C. She had concerns about her hepatitis C related health and was consulting a liver specialist and
considering starting treatment at the time of interview. In and of itself, however, she reported that hepatitis C was not the main reason she had decided not to have any more children.

I did plan to [have more children] but I didn’t stop [having children] because of the hep C, it’s because I’m 45. Sarah

Several women reported reaching an age at which they felt they must make a decision about whether or not to have children, and for those who decide to have children, when they will do so. For most women, this ‘certain age’ was at some point in their 30s, particularly when many of their peers had been having children and others began to ask them about their own intentions of having children or not. As described by Richards (1985), Theresa reported this to be a rather ‘confronting’ experience, in which others expected her to explain why she had not yet had children and why she might consider not having any. This demonstrates that there still remains pressure for women to have children, even if, as in Theresa’s case, they are professional women. Because Theresa’s reasons for not having children were mostly because she has hepatitis C, justifying her decision may have proved to be a problem; if she disclosed her hepatitis C she risks a stigmatised identity, but if she did not provide this reasoning then she also risked being stigmatised as she would be assumed to posses negative feminine identity traits, as identified by Hird and Abshoff (2001). Some of these women, in their 40s, reported having come to a final decision that they will remain childless, but for varying reasons. For each of these women, however, age was a major concern, particularly in relation to their hepatitis C related health and their ability to cope with the demands of motherhood.
You might [come to a final decision not to have children] but you
don’t have to make the decision then and there and then. As you
get a bit older, you know you have to make the decision then and
there. When you are younger, you are not sure what your lifestyle
is going to be like at a certain age. So you just slowly evolve. When
you get to the age where you sort of have to make a decision about
it, if your lifestyle is a certain way [IDU] but whereas when you
were young you probably did think the option might still be there
[to have children]. So you know there is that whole thing that you
are wasting your whole existence you are still using drugs, you are
getting near the end of childbearing age, you should be out there
having babies. It’s a really selfish thing [to use drugs]. *Sally*

Age I guess. I went through a period of wanting them [children]
but I just got over it. I was in my 30s. But I wasn’t desperate
enough to do it [have children]. If I really wanted it badly, but I,
not really, no. I just don’t feel particularly maternal, you know. I
don’t want one. *Tammy*

None of the women considered themselves to be ‘too young’ to have children, although 15
women reported that they suspected that they may be too old now to start having children,
or to have more children. This is likely to be largely explained by the age of the sample,
with a mean age of 35, ranging from 22 to 59 years. About two-thirds of the sample was
over age 30 and as such they were well within or above the age group in which Australian
fertility is now concentrated (Jain and McDonald, 1997).

In summary, as for most Australian women, age was an important factor in the
childbearing decisions of the women in this sample. However, the importance of age and
the issues that are associated with childbearing at older ages, are greater for women with
hepatitis C. Consequently, as found among this sample, we might expect women with
hepatitis C to have children at a younger age than they would have if they did not have
hepatitis C, or to decide not to have children because they have exceeded a particular age
or fear that in combination with age, they are more likely to become sick because of hepatitis C, and less able to cope with the demands of motherhood.

**Indirect effects of hepatitis C on childbearing decisions: Social support**

As discussed in detail in chapter eight, many women reported having a lack of social support, and particularly so in relation to childbearing and motherhood. Several women reported the importance of social support to them having children. This was reported to be particularly important because they had hepatitis C, as the physical and emotional effects of living with the virus often mean a greater need for both practical and emotional support and assistance. Some of the women who did not have children reported that their lack of support was a major factor in their decision not to have, or to postpone having children. The supports highlighted were both social supports, from family, friends and partners and formal sources of support, such as The Hepatitis C Council and drug users support organisations, as well as professional medical care.

Naomi’s lack of family support was a major factor which she reported to deter her from having more children.

*I don’t feel that I’d get the support because my boyfriend also has a mental illness. He’s very good with children and I think he’d be good with an older child, but not with a baby or a toddler. I think he’d find that stressful, you know. But you never know how they’re gonna react. My son’s father didn’t want me to go through with the pregnancy, and now look at him, he wants to look after him all the time, so, you know, you can’t say. There’s other things, like none of my family live in this country, so I wouldn’t have the help of grandparents or what-have-you. My boyfriend’s, both his parents died at like, within a month of each other, about 18 months ago, so there’s no grandparents on his side, and there’s no family to speak of for either of us in this country. Naomi*
Fiona reported that a lack of support was a contributory factor to her decision to have a termination recently. Although her sister had distanced herself and her children from Fiona, which Fiona perceived to be because she has hepatitis C, she turned to her for advice and support when she was pregnant. Her sister discouraged her from having the baby for financial reasons. This, along with a lack of support from the father of the baby and other factors relating to hepatitis C, further discouraged Fiona from keeping the baby.

He [father of baby] wasn’t, he didn’t bring it up. He wasn’t concerned, he didn’t really talk to me much about it, that’s another thing I didn’t have any support there. And I didn’t want him to say, you couldn’t have it, you know, and so I was quite fearful. And I felt I couldn’t be open, which affects relationships and you can’t be open and get everything out, everything dealt with. So you can both know what is going on, what each other is going through, being supportive. Emotionally, I was really out of balance and you know, I felt that that was a big part of it. You know, looking back to it and I suppose fear of never finding support. And I suppose with relationships, you’ve got, in the future sometimes, I fear if I will be able to have a relationship because I do have this [hepatitis C], you know. Fiona

Women who had children discussed how important the support and assistance they received from their family was in relation to caring for children. This support becomes particularly important when hepatitis C interferes with meeting their responsibilities as mothers. Kelly reported that she had a very supportive family, with whom she had a great deal of contact. Kelly’s family helped her to look after her children when she was not feeling well from the hepatitis C symptoms she experienced. Kelly’s sister helped to take care of her children when Kelly travels into the city for her hepatitis C health care. Kelly was confident that if she became very sick or even died from hepatitis C, then her children would be well cared and this is a great comfort to her.

They’ve [children] got a fantastic aunty and she’s more than happy to, you know, well she’s next of kin. So I mean that’s not an issue, they would be well provided for. But you know, it’s the whole
thing of their life, but you know it’s what I should be doing, and so I want to stay healthy and keep doing that. But they understand mum gets tired, and occasionally she does need to fall over and go to sleep for a while. They’re cool like that. You know, if anything happened to me, my kids would be well looked after. *Kelly*

Abby no longer had any contact with her family, who rejected her because of her drug use and her association with men who had been in jail. Her family also played a part in removing Abby’s child from her custody. Abby felt she would need more support when she had her second child (with which she was pregnant at the time of interview) because she has hepatitis C and was controlling her heroin dependency through methadone treatment. She greatly valued the support she received from her partner’s mother, and reported that she expected things would work out for them eventually because she had this support from her partner and his mother. She emphasised the importance of her mother-in-law’s non-judgmental attitude towards her, unlike many other people, including her own family. Abby believes that her partner’s mother did not judge her because she experienced similar problems to Abby in the past.

Because my family knew he [ex-partner] had been in jail and [family] are upper class and all that. They freaked out, and so with the hep thing and with the fact that I had a partner who’d been in jail. They wanted her [daughter] away from us, they didn’t trust the fact that I look after her, you know? Yeah, it [having hepatitis C] scares me, cause I think that one day…for the baby, but he’s [partner] very supportive and so is his mum, it’ll be alright. And she [partner’s mother] knows that I, we’ve got hep C. And she’s really supportive of the baby, she’s had three other children taken away from her, like when she was younger. And so she’s really supportive. She doesn’t care, she’s not judgmental or anything in that way. So, whereas my family on the other hand, if I’d gone in and told them things that, things that she knows about, my family would freak out. *Abby*

Dawn’s husband had recently been seriously ill and was hospitalised for several months. During this time Dawn was caring for their baby daughter full time and discovered she was
pregnant again. Although she did not see her family very much as they lived in South Australia, her mother came to stay with her to provide practical and emotional support. Dawn valued this support that was available to them when needed, even though they were not close by.

My parents I don’t get to see very much. Probably once, twice a year if I’m lucky, but like, if anything happened, like when [partner] was sick my mother was here. Yeah she [Dawn’s mother] was straight up here. I rang up and I was crying, [he’s] really sick, and she left and she was just there. And she stayed two weeks, went back home, and came back the next week. Dawn

When Jean was hospitalised with her hepatitis C symptoms several years ago, her son was still very young. At that time she had a partner on whom she relied very heavily for practical support. Now that she is older and no longer has a partner, Jean believed it would be too difficult and involve too many risks to have another child, including the risk of vertical transmission of hepatitis C.

It was lucky, yeah I had somebody, I had a partner at the time, which looked after me. Yeah if I hadn’t [had a partner for support] it would have been a huge problem. Jean

Linda wanted both her and her partner to start treatment for hepatitis C as both of them were experiencing significant and debilitating symptoms. She believed it would be possible for them both to have treatment at the same time, despite the side effects and other demands of treatment and the fact she had a 10-year old child, whom she was caring for full time. This, she reported, would be possible because she lived very close to her supportive mother, who would be able to help them out.

We [Linda and her partner] are both working at coming off the methadone, but while we are on the program I want us both to get the hep C treatment at the same time, so that when we are off, it
will be part of our normal routine of management for the rest of our life, because if we’ve got a plan we can stick to it. If we stick to it one of us might be lucky enough to get rid of it. I’ve got my mum two doors away from me so that is a damned good plus.

Linda

Not all women who were mothers had good support available to them from family. As a single mother who has experienced severe symptoms of hepatitis C, over extended periods of time, Jocelyn reported that she had really struggled because of a lack of support. She did not have any family in the country besides her children, who were in their late teens and at college. Now that they are older, Jocelyn was receiving some practical support from her children, and from her friends.

Support from partners

Nineteen of the 34 women interviewed had a partner at the time of interview. Sixteen of these women were living with their partner at the time of interview. Several women reported the support available to them from their partners to be very limited, largely because of their partner’s own drug use, and for some, mental health problems.

Some women reported that they struggled to care for their children when their partner had to go to jail, usually for drug-related offences. Amy decided that the last time her ex-husband went to jail that she would have no more children because she struggled to cope with caring for them alone each time he was in jail.

I didn’t want any more kids ‘cos he ended up going to jail. He went to jail and we split up because he used to belt me up. That’s why, he used to drink, he used to bash me up all the time, so I just left so I left him. And so I left him and my girls. Amy
Abby too felt very distressed and lonely when her ex-partner was in jail, and she turned to heroin to help her cope. She lost control of her heroin use and lost custody of her daughter in the process. Although Abby’s current partner appeared to be very supportive, his drug use and associated problems were a concern for her, especially in relation to having another baby. Abby agreed to have the baby on the condition that he stop using drugs and committing crime.

When I fell pregnant that’s when I enforced it on him, I said, ‘right, I’ll tell you right now, you either straighten up or I’m not having this baby and I’m not having you. I need to get my daughter back [regain custody] so there’s no use stuffing everything else.’ So he did, and he’s really done very well. Abby

Abigail reported her partner to need support, rather than to provide it because of his drug dependence. This did not prevent Abigail from keeping their baby when she discovered she was pregnant.

More needy rather. But no he, no he’s [father of her child] all right. He is supportive like, but he can be, I don’t know, too, he went through like a really strong period like when I was pregnant. And he got on methadone and got a job but he’s sort of slipped back a little bit. But he’s okay. He is good and he is supportive when I’m around, but more needy [than supportive]. Abigail

Three women reported their current partners to be abusive, mentally and physically, and other women reported having experienced living with an abusive partner in the past. The women placed great value on having a supportive partner in relation to childbearing and motherhood. Those women who reported their partner to be abusive did, however, also value the support they received from them, in spite of the abuse. Veronica’s partner was violent towards her and she believed the problems with their relationship were the cause for her returning to drug use after not using drugs and living a stable life for several years.
She believed the reason he was abusive towards her was because of emotional problems he has. As a result, he was unable to offer her much support. His abusive behaviour was of concern to Veronica because of the effect she perceived it may have on her children, as well as their forthcoming child with whom she was pregnant at the time of interview.

All I want is to see him take responsibility for that you know, and sort of stop blaming so much on everybody else and just cut back and say, this is me, I'm being childish, I need help. Yeah, he is very much [looking forward to becoming a father] but it's just our relationship, it's to the point where he has got that big question mark, will he be around long enough to be a dad? Will he end up getting himself kicked out? It probably weighs heavily on his mind, he doesn't have much to go to, it's pretty empty out there, for him. Where I will always have the home and the kids, always. But then again there is nothing stopping him from getting a room somewhere and getting a job or even just getting a job and staying with us. *Veronica*

Kylie and her partner had their four-year old child removed from their custody, largely because of domestic violence. Kylie was pregnant again at the time of interview and was still very distressed about not having custody of her child. She and her partner agreed that they would split up if they had to in order to avoid their imminent new baby being removed from their care also. They agreed that her partner would keep a separate flat where he would stay when he has been drinking, which is when he became violent. Kylie did not have any contact with her family and only had the support from her friend Emily, who was also interviewed for this study.

Well he [partner] knows he can’t [hit Kylie], but he also, he’s seen the pain that I go through, missing my son. He’s acutely aware of that. And I mean he loves, the times that we were all together he bonded with [son] quite strongly too, so I mean I think he was hurting over me losing [son]. I tried to knock myself [commit suicide] when I lost [son], took an overdose of sleeping pills. I mean [partner] and I will split before we lose this baby, we both acknowledge that. We’ve talked about it, there’s no way we want this to happen. But we would just be completely apart. He lives
just around the corner from where I do. It’s not as if he won’t be able to see his son. But, he doesn’t, I couldn’t go through that [having a child removed] again Clare, I could not. It would do me in and I know it would. *Kylie*

Sarah reported having been rejected by a sexual partner because he feared sexual transmission of hepatitis C. This partner also later accused Sarah of giving him a sexually transmitted disease, as he assumed that because she has hepatitis C, she also probably had other diseases that are similarly stigmatised.

*I was going out with someone before and I told him I had hepatitis C and he absolutely freaked out. *Sarah

When this happens, not only can this reduce the emotional and practical support available to these women, but may also limit the likelihood of them becoming pregnant by reducing the opportunity for sexual contact. Some women reported fearing such rejection among potential partners, and for this to create a barrier to forming new relationships, particularly with people who were not current or past injectors. Julie reported that she does not want to have a child with her current partner, as she does not believe he would make a good father. Julie’s current partner also impeded her efforts to stop using heroin, which reduced her ability to be a good mother. Only when she finds a partner who she believes will be a good father, would she consider having children.

Although male injectors often have female partners who are not injectors, this is not the case for women injectors, who tend to have partners who also inject (see chapter three). Rosenbaum (1981) reported that heroin users are ‘excluded from the straight world’ because they are assumed to be of poor moral character; and heroin users avoid interaction with ‘straight’ people (non-users) as ‘straight’ people are assumed to be intolerant and judgemental. Because of this two-way suspicion and fear, it is difficult for these groups to
integrate and so injectors remain marginalised and immersed in the drug-using world, particularly women. Even for women who no longer inject, their spoiled identity as a past injector can prevent them from fully reintegrating with the ‘straight world’ and thus their marginalisation persists long after their IDU has ceased.

I don’t tell anyone [about having hepatitis C], and my partner is a user anyway, but I can imagine that if I was to meet like a straight [non IDU] guy and I’d have to tell him and I don’t know what the reaction would be and also I don’t tell anyone else at all. *Julie*

Becky reported her hepatitis C to contribute towards her marriage breakdown and this was closely related to her inability to have children, for reasons relating to hepatitis C as well as underlying fertility problems. Becky described how she felt when she was diagnosed with hepatitis C.

I was pretty broken actually. After that my husband was angry with me for having, before I met him, contracted hepatitis. He had ideas of this family he was going to have, these kids he [was going to have]. I don’t know [it was] something that he didn’t want to have to deal with. *Becky*

Becky’s husband did not appear to have been concerned about the risk of sexual transmission. Becky perceived that he was more concerned about the implications of Becky having hepatitis C for having children.

The only thing he wanted from me was sex and he wasn’t worried about the hepatitis, for him catching it through sex, he was more worried about the trouble what I’d cause or him having a child that was hep C. *Becky*

When diagnosed with hepatitis C, Hannah was very concerned about how her husband would react. When she told him, they were both very concerned about the risk of sexual
transmission. However, her partner’s doctor assured them that the risk of sexual transmission was so low as to not warrant too much concern and Hannah’s partner had always been very understanding and supportive. They had recently decided to start a family and have their first child, and Hannah was happy that she suspected she was pregnant at the time of the interview.

I rang him [partner] up. Because I’m always going to the doctor and he’s always sending me off to the doctor because I’m always ill. I’ve been for years to the doctor, so that was fine, and then when I told him [she has hepatitis C], ‘shit! Really?’ And then I, it stirred up a little bit of this and that, but, then when he went to the doctors and he didn’t get it [hepatitis C] and she [doctor] said it’s all [having sex] very safe and just be careful and all that sort of thing. But, it was all fine. Hannah

Theresa was in a long term relationship with the person she had been injecting with when she was diagnosed with hepatitis C, and she remained in this relationship for several years afterwards. When she met her current partner two years ago, however, she was very concerned about the risk of sexual transmission and this was a source of anxiety for her and presented possible strains on the relationship.

I’d been in a long term relationship with the person I was injecting with, and we had broke up, and I’d formed a new relationship two years ago. I’d not even thought of sexual transmission or anything like that. So I had to ring them [Hepatitis C Council] up and talk to someone. They were very helpful. Theresa

Sarah told her husband that she had hepatitis C, and he reacted with concern for her wellbeing, and had always been very supportive. He had some concerns about her having hepatitis C in regard to having children, because of the risk of vertical transmission, but they agreed that it was a risk they were prepared to take and went on to have a healthy baby boy.
Well I mean, you go out with someone, you find out they’ve got disease, and they still love you. *Sarah*

Several women reported that having a child was an important way to cement their relationship with their partner, and that this was a major factor driving their desire to have children. Also, some women reported that they would like to have a child, but they needed to find an appropriate partner with whom to share the parenting responsibilities first.

If he [prospective partner] was everything that I put in that box of being ‘Mr. Right’ and husband material and father material then I would think that we would do the best we could to reduce the risk [of vertical transmission]. *Ellie*

Some women reported that their partners also had hepatitis C and that they incorporated this, and their hepatitis C related health into their childbearing decision, as well as their own hepatitis C. Jessica’s partner also had hepatitis C and was experiencing more severe symptoms than Jessica. Although Jessica had a daughter, her current partner was not the father. It was important to them to develop their relationship and build their family by having a child together, but Jessica did not want to delay this for too long as she feared her partners’ health to be deteriorating, and her own health appeared to be becoming more precarious over time and this may restrict what they are able to offer their child as parents.

My partner’s sick. He wants children of his own and [daughter] wants siblings. She wants a brother or sister. She gets pretty lonely as an only child. *Jessica*

One woman with children reported that she had split up with her partner, but that they still lived together in order to care for their children. This provided a good source of parenting support, but is not appropriate for everyone, particularly when the relationship has not ended amicably.
Formal support

Formal support that the women reported to be important to them focussed upon medical supports, and those from support organisations that exist to provide various forms of support for both people living with hepatitis C and injectors. Several women reported that their doctors had advised them to cease drinking alcohol in order to reduce the chances of liver damage through hepatitis C, but they were not offered any support to assist them to make these changes. While none of these women had any medically defined dependency on alcohol, they reported drinking alcohol to be an important part of their social life, and an everyday way to relax. These women felt that they needed some assistance with making, what were to them, big changes in their lives. After discovering how harmful alcohol could be to her because she has hepatitis C, Kate was talking to a counsellor about strategies she could employ to help her reduce or stop drinking altogether.

She should have referred me, or at least given me numbers to call up, like a councillor or something. I stopped [drinking] straight away and I was really good, but I fell back into a bad routine there for a little while and that’s when I went to the [hepatitis C information and support] night at [X hospital] and they had these little cards there and I thought, I’ll give them a call, and just have a bit of support and get some tips on you know, not to drink too much. But I think it’s okay for these doctors in their ivory towers to say, don’t do this and don’t do that. So now I’m really trying to be strict and I’m speaking to a councillor for alcohol and drug abuse, not that I drink a lot. And he said, ‘usually you wouldn’t even be, I wouldn’t even talk to you, but because you’ve got hep C and you’ve got a reason to really want to limit your alcohol intake.’

Kate

I thought, he [liver specialist] said for me to go and see somebody else. I thought, all these nobby people telling me I that should do this and that I should do that and that I felt like I had changed my life since I found out [she has hepatitis C] anyway. Hannah
Justine reported that her suspicion that she would have little formal support from doctors available to her if she were to have a baby, is a contributory deterrent to her having children. In particular, she reported that she was very fearful of encountering further discrimination relating to her drug use and hepatitis C, which she anticipated will be even worse from antenatal care medical professionals because of their focus on the wellbeing of babies, rather than the mothers (Oakley, 1993). Additionally, there are expectations of mothers that she did not feel she would fulfil, mainly because of her hepatitis C that indicates her drug use, and feared she would be judged on this. This is similar to Klee’s findings (2002a) among pregnant drug users in the UK, but in the case of women with hepatitis C, they carry a double stigma because as well as being an indicator of IDU, hepatitis C is also an infectious and potentially fatal virus.

I don’t have any, I mean, I have just had only bad experiences with doctors for so long and I really am, opposed to kind of, conventional ideas that there be. I wouldn’t feel like there is great supportive service out there now. Just, yeah the lack of medical support and. I haven’t really thought about the logistics and practicals of it [having children] really seriously but I would be concerned about, obviously having births in a birthing centre in a hospital. Obviously I would have to disclose to them that I have hep C. I mean of course I would. And I would be really concerned about that [the effects of disclosure of hepatitis C upon her medical care]. I would be very neurotic and anxiety ridden about getting the best treatment and I think too, just because I have become really inept at seeking medical help generally just it’s so long and it’s a whole new world it would be a really difficult thing for me to do. Justine

Support from organisations

Support organisations that exist for injecting drugs users and for people living with hepatitis C, such as the Hepatitis C Council were reported to be useful by the women interviewed, especially for the non-judgemental information they provide. In particular, the regular publications that several organisations produce were reported to be valued sources
of credible information. In relation to childbearing, these agencies were, however, reported to be very limited in what they were able to offer, largely because of a lack of specific knowledge about childbearing and hepatitis C. It is not the case that these agencies were poorly informed, but there is a lack of scientific knowledge surrounding hepatitis C and childbearing, and often information that does exist is conflicting. Consequently it is almost impossible to offer any information or advice with any confidence. This indicates the need for further research into this area, which extends beyond the risk of vertical transmission or the potential effects of pregnancy on the health of women with hepatitis C. Research is required to develop standardised information for medical professionals and support groups alike to provide to their clients. The social issues that are important to many women with hepatitis C have been severely neglected in research. Support agencies were, nevertheless, reported to be useful in providing information and support on practical issues that may affect women with hepatitis C indirectly, such as employment, health services and legal advice as well as referring them on to other sources of help.

Kate had recently attended a hepatitis C support group meeting for people with medically acquired hepatitis C. However, because she had no one to look after her children while she went, she was forced to take them along, which made it very difficult to participate in the group, despite the efforts and encouragements of the members of the group. Whilst the existence of the group is encouraging, it must be flexible and be accompanied by other supports to enable people to contribute to and make the most of it.

I couldn’t get someone to take care of my children so I had to take them [along to the support group meeting] and it was just a nightmare. And it would have been great if I were there and didn’t have the children with me. But they [the support group members] encouraged me to go still. But I, you can’t do it with two kids. Not at the ages mine are at. Kate
Summary: Women with hepatitis C have lower levels of social support and this affects their childbearing decisions

The data indicate that having social and formal supports is very important for women with hepatitis C, particularly in relation to childbearing and motherhood. The ways in which these supports are required have been demonstrated using examples of occasions when mothers in this study have drawn on these supports in times of need. Childbearing and motherhood requires both social and formal sources of support, but particularly so when the mother, or potential mother has hepatitis C. Hepatitis C presents many social and physical challenges that the general population do not have to deal with, and so additional support is often required to enable women with hepatitis C to have and care for children. There exist many other health conditions that can limit women’s mothering abilities in some way, such as a disability, for example (Holland Baskin and Riggs, 1988). However, the social meanings given to different health conditions can mean that different forms of social and emotional support are required, in addition to physical support.

Having a perceived lack of supports was reported to have some influence over childbearing decisions, particularly when combined with other hepatitis C related factors, as well as non-hepatitis-C related factors that influence childbearing decisions. Other women living with chronic health conditions and disabilities also need additional practical and emotional supports, however, the magnitude of stigma associated with being a mother with hepatitis C requires further emotional supports, which appear to be lacking among women with hepatitis C.
Injecting drug use affects childbearing decisions among women with hepatitis C

Because of the close association between hepatitis C and IDU, those women who have never injected illicit drugs are also likely to face at least some of the problems faced by current and past injectors who have hepatitis C. Many of the issues surrounding hepatitis C and childbearing are paralleled by those issues associated with childbearing and IDU (Klee et al., 2002), with considerable overlap because most women living with hepatitis C are current or past injectors.

All of the women interviewed reported that the biggest problem they faced because they have hepatitis C was its close association with IDU, which is a highly stigmatised behaviour. As such, women with hepatitis C are assumed to have the characteristics normally associated with the stereotypical injector, or ‘junkie’. Like most women with hepatitis C, the vast majority of the sample was current or past injectors, with only a small minority never having injected illicit drugs. These characteristics are considered to be in conflict with the qualities required for successful motherhood, according to the contemporary ideology of motherhood as defined by Wearing (1984).

One woman reported going to her GP for assistance in finding a detoxification facility. Rather than providing this assistance, the GP instead advised her that she should be having babies and doing what she is meant to do as a woman; being a mother, and not taking drugs. This incident is a reflection of some of society’s perceptions of women’s social roles; their primary role is of mother. The characteristics of injectors, and thus women with hepatitis C, conflict with notions of femininity and female social roles, as has been highlighted in extant literature (Klee and Jackson, 1998; Lawler, 1996; Rosenbaum, 1981).
Although several women complained of segmented health care (as discussed in chapter eight) it was also the case that some medical professionals appeared to take on a directive, rather than informative role. Unfortunately, these medical professionals were often reported to be uninformed or misguided in their approach.

Although several of the women who reported being current injectors in the sample were dependent on illicit drugs, not all of them were, or ever had been. About 18 women had been dependent on heroin and were on a methadone maintenance program at the time of interview, but some of these women did also inject illicit drugs, and sometimes injected methadone. Additionally, at least two other women had also been on methadone treatment prior to the interview. On the whole, those who were on a methadone maintenance programme were generally quite stable and had control over their lives, even if they did sometimes also inject illicit drugs. Dependence on methadone, even within a maintenance program, has unique problems within and of itself (Southgate, 2003), and was also reported to be an important consideration in childbearing decisions. In particular, the women were fearful that by having a baby whilst on the methadone program, their baby may experience distressing and harmful withdrawal symptoms, as well as presenting social and health care problems.

There were similarities in the risk perceptions of maternal drug use during pregnancy and the risks associated with vertical transmission of hepatitis C. Although there is a lack of clear evidence on the effects of maternal methadone or illicit drug use through pregnancy on the foetus (Hepburn, 1996), there exists much medical advice on the issue, although it is often conflicting. Consequently, the women in this sample reported receiving conflicting information and advice on the risks of their baby experiencing withdrawal symptoms from their methadone or drug use. The interview data indicate that both lay people and medical
professionals have a strong opinion about drug use during pregnancy, which appears to be influenced by their opinions of woman’s drug use and the social position of mothers based on the ideology of motherhood. Because of this conflicting advice and information, some women reported being very sceptical about information they receive from medical professionals regarding the effects of maternal drug use on their babies.

Women who have babies whilst on methadone are often judged harshly (Boyd, 1999; Waldby, 1988), and blamed if their baby experiences withdrawal symptoms (Klee, 2002a; Klee, 2002c; Klee and Jackson, 1996; Klee and Jackson, 1998). The fear of guilt that the women reported about the risk of vertical transmission of hepatitis C was just as, if not more, evident with regards to the risks associated with maternal drug use throughout pregnancy.

Some sources of information regarding drug use during pregnancy were considered to be more credible than others. For example, Dawn and her husband consulted inner-city medical professionals and people from organisations who regularly work with drug-using mothers and women with hepatitis C. Because these professionals had a great deal of experience with drug-using mothers and women with hepatitis C, particularly in relation to childbearing, they considered the advice they received from them to be credible and not morally based in the same way as they expected from less knowledgeable and less experienced sources.

Those women who were mothers whilst drug dependent reported maintaining both these roles, as drug user and mother, to be very difficult. When these mothers with hepatitis C are sick, unlike with other social roles, they cannot take time off to recover. Being a mother is a full time and very demanding commitment, which is can be too much to deal with as
well as maintaining a drug habit (Barnard and McKeagney, 2004; Rosenbaum, 1981; Taylor, 1993). Those women who were not drug dependent mothers reported that they expected this would be extremely difficult, and a situation that should be avoided. Rebecca had decided not to have any more children, and this decision was largely attributable to her drug dependency. Each time Rebecca went to prison because of crimes she had committed in relation to her drug use, her own mother and the father of her child cared for her son. However, Rebecca’s main concern was that her drug use might physically harm her child.

I don’t want any [more children] because I’m a drug user and because of hep C. Rebecca

Several women reported feeling guilty about their IDU and the effects this has, or may have on their children, and try to make up for what they perceive to be their shortcomings. Kylie was injecting her methadone (she has never used heroin, only methadone) and felt guilty about the effects this might have on her child.

He [partner] doesn’t like me being on methadone. He is not an IV user, never has been, smokes pot and that’s it, has a drink. He doesn’t like me being on ‘done’, he knows I am, and we’re both worried about [unborn son] maybe having to be medicated. And that’s a big guilt burden on me, you know. Kylie

Several women reported that they believed it is morally wrong to have children whilst dependent on drugs, and thus subscribe, at the very least, to this aspect of the current ideology of motherhood. This has been found in other studies of drug-using women (Klee, 2002b) and for the same reasons (Rosenbaum, 1981): the risk of the baby withdrawing after birth, as well as permanent associated damage from exposure to the drugs; expectations that drug dependent women are unable to provide adequate mothering; and that the children of drug-using mothers are likely to become drug users themselves. Much of their
concern was reported to revolve around the risks of their baby being born with drug dependence and experience withdrawal symptoms. Those who had continued to use drugs or remain on methadone treatment whilst pregnant reported this to be an undesirable situation and they felt guilty about it. Kylie was on methadone when she had her first child several years ago, and although not serious, her baby did experience some discomfort, which she attributed to her methadone use whilst pregnant. Pregnant again, she was very fearful of her forthcoming baby experiencing withdrawal symptoms as she was still on methadone treatment, but felt she was not as strong and healthy as when she had her first baby.

My baby is going to get my heroin and hang out when I hang out, I have had three friends have babies in the last few weeks and they are all users and … no I don’t believe in it. I didn’t use. I stopped using [when I was pregnant]. So my baby would not hurt, I don’t believe in it. Now look at these three women [who] got their babies an hour after they were born [removed from their custody], you know what I mean. Rebecca.

Participants also reported that being dependent on illicit drugs dominated their lives, and as such they were unable to provide the intensive caring that is involved in ‘good’ motherhood. There was a great sense of immorality associated with having children whilst still using drugs (particularly if dependent) among the current and past injectors in the sample, as also reported by Rosenbaum (1981). The women in the present sample reported having rules that they and their partners followed in order to minimise any affects of their drug use on their children.

He [son] never saw nothing. He never saw me on the brink, he never saw me shoot up, that was one rule. There were strict rules. Rebecca
Some women reported that women who have children whilst dependent on illicit drugs, create more problems for themselves on the whole, than if they remained childless or did not have more children than they already had. However, this is not necessarily the case for those who inject but who are not dependent users and in fact have a stable, highly functioning life.

Rosenbaum (1981) reported motherhood to have a significant impact on the ‘addictive career’ of women heroin users, in which children provided motivation for reducing or quitting heroin use. Additionally, children were reported to maintain the connection between drug-using women and the wider community (Taylor, 1993; 1998). Some women in this study reported that becoming pregnant has had a positive effect on their drug use, in that it had provided them with a very good reason and motivation to cease or reduce their drug use, and improve their health. Several women in this study reported that they ceased or reduced their IDU when they discovered they were pregnant. This was a self-imposed measure, and like other lifestyle changes, represented an attempt to recreate their spoiled social identity. For example, Abby stopped injecting and went onto a methadone program as soon as she discovered she was pregnant and made the same requirement of her partner. Some of these women reported starting on a methadone maintenance program when they became pregnant. Although they would have preferred to have gone ‘cold turkey’ and stop using altogether, they were usually advised against this by medical professionals and instead stabilised both their drug use and their lives, through methadone and other drug treatments. Veronica wanted to stop injecting drugs and to come off methadone when she became pregnant, but was advised against this by her doctor.

Yeah I do I plan to get off methadone as soon as I have this baby.
I wanted to come down before but I can’t, but as soon as it’s gone
I’m going to chop a big lot off the dose because I can afford to do
without about 30 mils, I am on 90, I'll come right down to a comfortable place. Then I will wean myself off it in the next eight months or so and then I can start again on my health trip I know I can do it and I love it it’s great. *Veronica*

Several women reported knowing of other women who continued to inject throughout their pregnancy, or remained on methadone treatment. These women were scorned upon even by other injectors and friends who are sympathetic and understanding of their problems.

*It depends on circumstances. Where some one uses drugs or is on methadone and I see it all the time, even at the methadone clinics even other drug users sometimes. Like comments about, you know, look at her she's still using, even from other druggies. Imagine what it’s like in society. It’s like that look you see on people’s faces if they see a pregnant woman smoking. *Sally*

Some women reported their IDU to be a major factor, if not the most important factor in their childbearing decisions. Some reported that they had terminated pregnancies in the past because of their IDU, particularly when they were highly dependent users. These women also reported that their partners’ drug use was also factored into their decision to terminate the pregnancies.

*I’ve had a couple of terminations, quite a few, like four or something. I’ve had one miscarriage. [Q: Why did you decide to have terminations?] Well with [name], that’s the man I was with for nine years, just under nine, [first child’s] dad. We were both using and it was not, just was not the right time for us to bring a child into the world. Not that we didn’t love each other, because we did and we were both good parents and we both love our son. The timing was wrong and I’ve been pregnant to [current partner], I’ve been with him for five, nearly five [years]. Our relationship wasn’t strong enough, it wasn’t the right time, it was relatively early for us. This time now, it was his idea, that we have a baby. One Sunday, early, at the beginning of this year, he said ‘I want you to fall pregnant.’ Just like that, right out of the blue. It threw me, blew me away, straight away. *Kylie***
Their partner’s drug use not only affected their ability to be a good father to the child, but also influenced the woman’s ability to control her own drug use and gain control over her life, as has been found in other studies (MacRae and Aalto, 2000; Miller and Neaigus, 2001). Other women reported that they would not have a child, or another child, until they had their drug use under control, or had completed their methadone treatment. At the very least, most women who did not have children at the time of interview reported that they would reduce their drug use or methadone dose if they became pregnant. The reasons they gave for this centred around the risk of harm to the baby through exposure to these drugs during pregnancy.

I would probably start reducing and get down to a low dose. I’d like to be off methadone before I got pregnant. But if I fell pregnant while I was still on the methadone I would come down to a low dose that you are not allowed to jump off while you are pregnant because you could miscarry. So I would at least come down to a low dose like under 30 and above 20. Somewhere between 20 and 30 and just stay on that. I’ve got a friend actually who has had two children, she is having another one and both children she had on methadone but the kids didn’t hang out at all. Usually they have got a bit of … in their muscles when they are on methadone. But those children were fine. She took them both home from hospital a day later, two days later or something. Both pregnancies were on methadone and it didn’t seem to go through to the children and it was really, really weird and the doctors and the nurses were amazed. They were like, you must have a miracle body because these children aren’t withdrawing at all. And she is pregnant again and so that’s good for her, except one of the boys are a bit hyperactive, that’s the only thing she can say. *Ellie*

In the interview, Becky reported that she did not want to have a baby whilst she was still on methadone. However, Becky became pregnant soon after the interview and had a healthy baby. Based on the medical advice she received, she remained on methadone throughout her pregnancy. This demonstrates that childbearing decisions can be flexible and are not always planned decisions, as discussed in Moos et al (1997).
Now I would never think about having children when I was on methadone. I wouldn’t want to. Becky

Some women reported that women who are known to have used illicit drugs, have to prove to authorities such as social workers and hospital staff their ability to mother, far above and beyond what is expected of other mothers, as did the women in Taylor’s study (1993; 1998). Dawn reported her frustrations with her antenatal care, which she believed to be related to her being on methadone. For her, being on methadone serves as a social label, which informed medical staff and authorities involved in the care of she and her family, that she was at high risk of a number of problems. In particular, Dawn felt that because she was on methadone, the medical staff and social worker to whom she was assigned, believed she may not be a fit mother. Consequently, like other women identified as drug users, throughout her antenatal care and after her babies are born, Dawn and her partner will be monitored far more closely than other non-drug-using mothers.

While there is strong evidence that parental drug use is associated with child abuse and neglect (as discussed in chapter three), there is also substantial evidence that drug-using parents can in fact be quite able parents and that drug-use does not necessarily mean that they are abusive or neglectful parents (Jackson and Klee, 2002; Klee, 1998). It is simplistic to assume that drug use itself results in harm to children. Other factors that are often present among drug-using parents that may contribute to child abuse or neglect include poverty, psychiatric disorders and other social factors (Boyd, 1999; Klee, 1998). Dawn and her partner were both very stable and had been on the methadone program for some time with no problems (that they reported) and stated to have not been injecting drugs. They held values very similar to those expressed by the authorities about individual responsibility, in regard to the care of children, and felt frustrated that, despite their efforts and no other indicators of problems, that they were subject to this surveillance. Dawn and
her partner believed that because of this, rather than being a source of support, the antenatal and social services are actually acting as a hindrance to their parenting.

We’ve had social counselling, we’ve had drug counselling twice now at the hospital, for no other reason than I’m on methadone. And DoCS [Department of Community services], apparently DoCS get called in too now because you’re on methadone and also, you have to stay in hospital for seven days, you can’t get out any earlier than seven days. That’s for the baby, to make sure the baby’s not withdrawing. That’s okay if you haven’t got other kids and stuff to look after I suppose. It didn’t really matter with [existing child] but now it does. I was on 10 mils [of methadone] more then [when she had her first child]. Because I want to get off the ‘done’. But no, she [first child] didn’t have any problems at all. So we’re hoping, I’ll put in a request for an early, for a liaison discharge which means that the midwife can come round and see that she’s all right. After four days, instead of staying in for seven days. Because I can’t just leave [existing child], you know, she’s going to freak out, and then I come home with a new baby. I’m a bit concerned about how she’s [daughter] going to cope with it all. The sooner I come back the better, and then the midwife can come round here. I mean like I said I’m on 10 mils less now, so I really don’t think there’s going to be any problem. *Dawn*

Dawn had some concerns about the risk of her baby withdrawing from methadone. She felt that she would be able to spot any signs of distress, and was frustrated because she is not given the responsibility to do this for her own baby. Hepburn (1996) found that drug-using mothers were just as vigilant as hospital staff in observing their babies for signs of withdrawal, indicating that drug-using mothers should be given more responsibility, where appropriate. The additional surveillance that Dawn and her husband were under, and the additional time they were expecting to be forced to stay in hospital after the birth of their second child would make caring for her existing child logistically more difficult, because the extra support that is required was not provided. When she protested, she was then labelled as difficult.
We got down to 25 before we had this baby, and 35 for her [first child]. And that's why I feel pretty confident about this one, because she didn't withdraw on 35, so why would this one on 25? But it depends on the person, it doesn't mean he won't, you know he still can [suffer withdrawal]. But you know they're there at the hospital and they give them morphine drops and stuff if they have to. And you just hope that's not necessary. I mean I'd rather him be a little bit jittery for the first couple of days, than have to be on them for months and then be weaned off, because you still have to get off that jitteriness when he gets taken off it in the long run. But you just don't want to see that because you get into that, well I do, well shit he's like this because of me, I've done this to him, and look how uncomfortable he is. *Dawn*

As is common among heavy drug users, some women reported becoming pregnant when using drugs heavily, because they believed they could not get pregnant. Often, heavy drug use causes menstrual periods to stop, causing women to believe they cannot conceive. It is in fact possible for them to still conceive and many do (Klee and Jackson, 1998). Weber et al (2003) report that despite the widely held belief that drug-dependent women are less fecund than other women, they are in fact just as capable of becoming pregnant. Some of the women in this study who reported becoming pregnant under these circumstances kept their baby, whilst others had a termination, largely because of their drug use.

As has been reported in other sections, many women avoided health care professionals. They did, however, appear to generally be more willing to attend services that specifically target stigmatised groups and treat stigmatised diseases, such as sexually transmitted infections and drug and alcohol problems. This is because these medical professionals were perceived to be less judgemental and less likely to discriminate against them because of their IDU. However, these medical professionals were generally not in a position to provide them with advice and care concerning pregnancy. Antenatal care in particular was considered to be a potentially very confrontational situation, because they felt that as injectors, they did not ‘fit in’ at such care centres, and greatly feared discrimination based
on the fact that medical professionals would consider them to be unfit mothers (Boyd, 1999; Hepburn, 1996; Klee and Jackson, 1996).

When pregnant drug users present for antenatal care and are treated discriminatorily, this acts as a deterrent to them showing up for the rest of their antenatal care, and often they do not attend for care again until they give birth (Klee and Jackson, 1996). Again, these women are judged harshly for this, based on them being perceived as irresponsible and placing the baby at risk through both their drug use and not attending for antenatal care (Klee and Jackson, 1996; Rosenbaum, 1981). However, Dawn, a past dependent IDU on methadone maintenance, shared these values.

If you miss, like if you just didn’t go to any of your appointments. You’re pregnant, like you go to the doctor, and have your pregnancy test done to confirm, and then you never go back until the baby’s born. That’s why it’s neglect. And it is neglect too because you should know if it’s healthy. *Dawn*

Overall, IDU, particularly dependent use, was reported to be a source of great instability in the lives of many of the women interviewed. This was perceived to be an undesirable situation in which to have and care for children, and often led to children being removed from their custody, voluntarily often to the care of family members, or enforced, in which their children are placed into government care. Abby had her first child removed from her care and the child was in the custody of the father. Abby was determined that this would not happen again, and believed that by stopping her drug use and making her life more stable in doing so, and by making the same demands of her partner, then they would create a better situation in which to have their imminent child.
I said to Paul, you want me and you want this baby I’m not gonna live in this junkie lifestyle ‘cos my family never brought me up that way. I don’t like it I could never live that way. *Abby*

IDU, especially when accompanied by dependency, has effects on the physical and emotional aspects of women’s health as well as seriously reducing their SES (Blume, 1990; Broom, 1994; Byqvist, 1999; Ettorre, 1994; Goldberg, 1995; Klee, 2002e; Mason, 1991; Oppenheimer, 1991; Taylor, 1993). The health and social effects of hepatitis C act to compound the effects of drug dependence to create a situation in which it is extremely difficult to be what is known as a ‘good mother.’ For example, Amy tried to maintain a good relationship with her children even though they were no longer in her care. However, her ex-partner used her drug use and hepatitis C statuses against her, to discount her to her children and attempt to restrict her relationship with them.

In being an injector, many women with hepatitis C are often assumed to be an unfit mother, regardless of other aspects of their circumstances. These deviant labels are very difficult to shed and lead these women into secondary deviance as legitimate means of achieving their needs are closed off to them. This further restricts assistance which may be available to them.

Some women reported that their current drug use, or being on a methadone program was of far greater concern to them in regard to childbearing decisions, than hepatitis C.

I was more concerned about the methadone than the hep C to be honest. But yeah methadone withdrawal is a lot more of an issue to us than hep C was and that’s for sure. *Dawn*

Most women who were injectors or on a methadone maintenance program, however, had childbearing concerns that related to both their hepatitis C and IDU, which for them, were
inseparable. For these women, there was considerable overlap in the issues associated with IDU and hepatitis C in relation to childbearing decisions. Hepatitis C and IDU are indicators of each other, and when found in combination, they compound to increase the negative effects of each of these negative social labels and all that they are associated with.

Women who had never injected illicit drugs experienced some of the same problems relating to motherhood as the current and past injectors. This is because people with hepatitis C are usually, rightly or wrongly, assumed to be current or past injectors. The women who have never injected used strategies to try to reinstate their status as a non-injector to reduce the negative consequences of the injector label. This, they reported, resulted in less discrimination in both social and medical settings. Several of the current and past injectors attempted to assume a ‘never-injected’ status in order to reduce the discrimination and judgement they face from many people, but they were not always believed, particularly if their other characteristics (such as being poor) indicated that they might be injectors.

The issues surrounding childbearing among injectors, current and past, are evident for most women living with hepatitis C. However, having hepatitis C serves to compound the problems associated with maternal drug use. Having hepatitis C adds credibility to the suspicions that as an injector, these women pose risks to others, particularly to their children. Within the current social construction of motherhood, in which a mother must put her child’s needs above and beyond her own, this is deemed unacceptable by both the lay public and many medical professionals.
Existing children and hepatitis C related childbearing decisions

Twenty-two of the 34 women interviewed had children at the time of interview and six were pregnant. Women who already had children related current and future childbearing decisions to how their hepatitis C may affect their existing children, and the possible effects of another child on their own health and the wellbeing of their children.

Some women reported the hepatitis C status of their existing children to influence their childbearing decisions. For example, Kate reported that if her second child tests negative for hepatitis C, then she will have a third child. Kate was waiting for the result of a hepatitis C antibody test for her second child at the time of interview.

I think I’d like to have another child, um, but if she has got hep C I just couldn’t, couldn’t imagine like, putting another child through that, you know. *Kate*

While Kate perceived that if her existing two children did not have hepatitis C, then the chance of her third child of having it would be very low. Kelly, however, looked at a similar situation quite differently. Kelly perceived that having had two children who had not contracted hepatitis C from her has been lucky. By having a third child, she felt she may be stretching her luck, and the chances of a third child also testing negative would be reduced. These women demonstrate that despite being in similar circumstances, the way in which risk is perceived is open to very different interpretation.

I had my son tested at 12 months, because for the first twelve months they carry mum’s antibodies. So he was carrying the virus, well from what I was told he was carrying the virus. And yeah, so at 12 months I had him tested and he didn’t have it. And well I kind of took the chance with her. Yeah, but knowing, I mean I think the only thing that would stop me is I’ve been lucky twice. Third time, I couldn’t push it. *Kelly*
Several women reported that they did not want to have any more children because they had borne and cared for all the children that they wanted. This was not related to their hepatitis C. For these women, this was generally a lifestyle decision, often in combination with age because if they had more children in addition to those they already had, they perceived this would restrict them from doing things they wanted to do that they had so far been unable to do because they have children.

No [does not want any more children]. But that’s not because I’m hep C positive it’s more a lifestyle choice yeah. Janice

Amy had seven children, but only one of her children was living with her, the rest were all in the custody of their father, her ex-husband. Amy reported that she did not want to have any more children. Other women, with only one or two children, however, also reported that they did not want any more children, and that they had fulfilled their role as mother.

**Summary: Hepatitis C and injecting drug use impact on childbearing decisions**

Many women who had children reported that their childbearing decisions related to their hepatitis C. They were concerned about their own hepatitis C related health and whether or not it would be fair to their existing children as well as any prospective children to have more children. Perceptions of the risks involved in having more children, for example, the chances of having another child who is free from hepatitis C, varied considerably for different women in similar circumstances.
Overall, the women indicated that they were more likely to have smaller families because they have hepatitis C, than if they did not have hepatitis C. This was because they are concerned about the effects of more children on their health in relation to hepatitis C, and also because they perceived they were capable of mothering fewer children because of the physical, social and economic limitations imposed by hepatitis C. However, because of their limited life options, they were not willing to relinquish their role as mother, as the status of mother affords them social status they would otherwise be unable to achieve.

Although motherhood remained the only viable option for many of these women in order to achieve a legitimate social identity, the stigma associated with hepatitis C and IDU continued to leave a stain on their social identity despite any attempts to recreate their spoiled identities though behaviour and social role changes. This was because deviant identities are often permanent and all other identity characteristics are seen though the filter that a stigma creates. For most women with hepatitis C, their deviant identity remains their master status.

This chapter has demonstrated the many ways in which living with hepatitis C can impact upon childbearing decisions. The next chapter goes one stage further and explores the effects of hepatitis C upon the experiences and meanings of the role of motherhood.
Chapter 10: The Meaning of Motherhood for Women with Hepatitis C

Twenty-two of the 34 women interviewed had children at the time of interview. Eight of the women with children reported that they definitely did not want any more children, and had completed their childbearing career. Women who had children were asked about their experiences of motherhood in relation to having hepatitis C. They reported on ways in which living with hepatitis C has affected their mothering experience and to what degree. In this section, women’s experiences of mothering with hepatitis C are discussed in relation to the social construction of motherhood.

In the previous chapter, many of the fears about motherhood were reported to influence childbearing decisions. In this chapter, women’s experiences of motherhood are shown to demonstrate that many women’s fears are in many cases justified.

The desire to be a mother

The reasons reported for wanting to become a mother or to have more children were varied but there were some common themes, as there are for women in the general population. Ross (1990) found that women injectors reported the same reasons for wanting children as women in the general population, with, however, some specific additional reasons. Similar to the women in this study, Ross et al (1990) found that women injectors perceived becoming a mother as an indicator of lifestyle change and a new phase in life. Ross et al (1990) concluded that women injectors had more reasons for wanting to have children than women in the general population. The reasons reported included wanting to
cement their relationship with their partner, to complete their union; to provide children with a good childhood, often that they themselves had not had; mothering being their primary role; to give and receive love; to feel needed; motherhood being a desirable experience; the threat of not being able to have children; to provide a sibling for an existing child; and to build a family. These desires for children appear to be socially driven and are rooted in social roles and norms. These reasons do not appear to be different from reasons we might find among the general population, although we may expect there to be more circumstances where there is a fear of not being able to have children because they have hepatitis C. Conversely, Cannold (2000) found that many women reported their desire to have children or not is related to their ‘biological femaleness’ in which they used biological knowledge to explain their desire for children. The women in this study spoke little of biological reasons for wanting children, and instead focussed upon social and emotional reasons.

For many women in the present sample, like those in Rosenbuam’s study (1981), motherhood represented an opportunity to achieve a legitimate social identity. In particular, women who felt they had failed in other areas of life perceived motherhood as an opportunity to do something right and redeem themselves. When Becky thought she would be unable to have children because she had hepatitis C, she was devastated and was forced to reassess her life plans. Like the women in McDonald’s (2002) study, there were some women, such as Becky, who were persistent in exploring their chances of becoming a mother despite some medical professionals having told them that they could not or should not have children. Rather than disregarding medical advice, Becky found an alternative opinion from another medical professional. Her diagnosing doctor had advised her that she should not, and probably could not, have children because she had hepatitis C. Other
doctors, whom she consulted afterwards, informed her that although there are some risks involved, she could still in fact have a child, but this is a decision she must make.

In a study of risk assessment of black American women, Hill (1994) found that women ‘obfuscated’ the medical knowledge surrounding sickle cell disease in order to justify their decisions to continue to have children despite being aware of the high risks involved for their children. The consequences of remaining a non-mother were perceived to be of greater enormity than the risks associated with sickle cell disease. For many women with hepatitis C too, the risks associated with remaining childless are greater than those associated with vertical transmission to a child, short life expectancy or experiencing debilitating symptoms.

**Choosing to be childless**

Five women indicated that they had no intention of having any children in the future, although one of these women had a child in her adolescence but it was taken from her at birth. All but one of these women were in their 40s or older and, as such, were approaching the end of their childbearing years and their decision can be assumed to be final. Sophie, however, who was in her late 20s, indicated that she had no intension of ever having children for several reasons. However, given her younger age, it is possible that her decision may be reviewed in the future.

Baum (1994) claimed that there are four types of women who choose to be childless, distinguished from each other by their reasons for remaining childless: The hedonists

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37 This woman is treated as a non-mother throughout the thesis as this is how she defined herself as she had not had the opportunity to care for the child, which is, to her, what motherhood entails.
remain childless to preserve their lifestyle; other women do not have any emotional feelings for children; idealistic women do not want to bring a child into an unsuitable world or contribute to overpopulation, and practical women have specific practical reasons for not having children, such as a career or the risk of congenital disease or birth defects. Three of the women in this sample who intended to remain childless worked in semi-professional or professional occupations, and another one as a receptionist. None of these women cited their career as a reason for not wanting children. The fifth woman who intended to remain permanently childless, Valerie, was unemployed at the time of interview and did not expect to gain employment in the near future because of her poor hepatitis C related health. With the exception of Valerie, these women have a higher SES than the majority of the group, which is a similar situation to that found among the general population, in which the women who are choosing not to have children tend to have higher educational levels (Australian Bureau of Statistics, 2003a) and higher rates of employment, in more professional occupations (Marshall, 1993; Morrell, 1993). They were all current (Sally and Tammy) or past (Sophie, Valerie and Theresa) injectors, who, with the exception of Theresa, had experienced significant dependency problems. Sally and Tammy reported that they did not want to have children, largely because their drug use was not conducive to good mothering, nor were they particularly ‘maternal’; i.e. orientated towards desiring to have and care for children. According to Baum (1994), Sally and Tammy may be perceived as ‘hedonists’, or ‘practical’, as well as ‘emotional’ childless women; their unwillingness to change their drug use, may be perceived as a hedonistic reason, but also as a practical reason. Sophie and Valerie had both experienced significant drug-dependence related problems in their life, which led them into sex work. Each of them felt that they have too many problems, including hepatitis C, to make a good mother, which would represent ‘practical’ problems; Sophie felt she would have to return to sex work to support her child, whilst Valerie thinks her poor health, insufficient income and lack of support would
present problems in meeting her maternal responsibilities. The women in this sample who have decided to remain childless have done so for reasons which may fit into Baum’s four categories (1994), but for more specific reasons largely relating to their drug use and hepatitis C.

Only one of these women, Theresa, who reported intending to remain childless, had a long term partner. Although a past injector, Theresa fits the profile of childless by choice Australian women more closely as a professional woman who cited lifestyle choices and her relationship with her partner in her reasons for remaining childless. However, Theresa also had serious concerns about the potential impacts childbearing and motherhood might have upon her hepatitis C related health, particularly as she had experienced severe and debilitating symptoms in the past. None of the women who had chosen to remain childless in this study, fit the typical profile of other childless by choice Australian women. In this sample, the reasons for remaining childless were quite different to those cited in literature on choosing to remain childless such as, the long term commitment, work involved, financial concerns, lack of support, compromising life goals, disruption to relationships, lack of maternal biological desire (Cannold, 2000; Lievore, 2001; Marshall, 1993; Morrell, 1993). However, the reasons cited by women in the present sample can be categorised using Baum’s system (1994), outlined above. Also, these women indicated that they did not reject the current ideology of motherhood. Like the women in Cannold’s (2000) and Marshall’s (1993) studies, they accept the requisites of good motherhood and because they were not willing, and in some cases able, to meet these requirements, opted to remain childfree. It seems overall, that women with hepatitis C who decided to remain childless, did so for different reasons than women in the general population, as do women with HIV (Bedimo et al., 1998; Duggan, Walerius, Purohit, Khuder et al., 1999; McDonald, 2002). With the exception of Valerie, the women in this study who had chosen to remain childless
each had careers and strong support networks, which along with other indicators suggests that they are not the most marginalised women in the sample by any means. They had other legitimate social roles. The extant literature on childfree women indicates that most women who choose to be childfree are middle class and non-religious; in particular though, these women have other legitimate social roles though which they build their social identity. Most women with hepatitis C do not have the same options as most women who choose to remain childless, as described in various studies (Cannold, 2000; Lievore, 2001; Marshall, 1993; Morrell, 1993).

There were other women in the sample who indicated that because they had hepatitis C, they might not have any or more children in the future. These women may or may not have children in the future but without a longitudinal study, it is not possible to assess which ones will and will not go on to have children.

Some women related their desire to be mothers to the degree to which they considered themselves to be ‘maternal.’ Women who had decided to remain childless often reported that they were ‘not particularly maternal’, as they presumed other women who had children to be. While the women who reported that they did want to have children referred to mainly social reasons, the women who did not want children explained their decisions based upon biological explanations; that they lacked the ‘natural’ desire for children. There is, however, little evidence to support the concept of a biologically driven maternal desire, although it is widely believed to exist (Lievore, 2001).

All of the women who had decided to remain childless, apart from Theresa, had deviant identities because of their drug use. All of these women considered hepatitis C to be at least a contribution to their decision to not have children. For Valerie and Theresa, however,
two very different women, hepatitis C was the major reason they have decided not to have children. Theresa, whilst she held a respectable social position with a professional career, was a past drug user with serious health considerations, not least her hepatitis C. Theresa reported feeling some pressure to have children over the last two decades, and for this to be confronting. However, she was confident about her decision to remain childless and was able to defend her decision to others. The other childless-by-choice women in the study reported that because of their drug use and associated health problems, the people close to them, who would normally exert pressure to have children, such as their families, have not expected them to have children because of these reasons. Childlessness among these women may be perceived as involuntary and as such does not violate social norms to the same degree as choosing to be childless, which implies rejection of social values. However, their reasons behind choosing to be childless are associated with highly stigmatised statuses and behaviours; having hepatitis C and being an injector. They could not openly reveal these reasons to others to demonstrate why they are not having children, for fear of rejection and other social sanction, and as such they are likely to be assumed to have rejected social values and be perceived as deviants. Most of these women who intend to remain childless have other legitimate social roles, particularly their working lives, and they have good social support networks. They did not appear to have suffered greatly as a result of remaining childless. However, for Valerie who was unemployed, being unable to become a mother implied greater social cost, as she had no other legitimate social role or identity. The negative impacts associated with not becoming a mother because of hepatitis C, as among the general population, are likely to be more severe for women of lower SES. Although Valerie did still have some choice to have children, because she did not have a partner and had so many health and social problems, her childlessness may be perceived as involuntary.
How does having hepatitis C affect mothering?

Living with hepatitis C was reported to present problems to motherhood, which would not necessarily exist if they did not have the virus. The women perceived that mothering would be easier if they did not have hepatitis C. Hepatitis C was reported to make achieving ‘good’ mothering, as defined by Wearing (1984), more difficult. It will be shown in this chapter that women with other chronic health problems also experience difficulties in their role as mothers, but the specific social issues that surround hepatitis C cause additional and different problems. Although as Swigart (1991: p7) states, ‘there are no perfect mothers on this earth’ as they are currently defined.

Supports

Women who lacked social support reported their hepatitis C related mothering difficulties to be significantly worse than those who had sufficient support networks. Living with hepatitis C and mothering requires extra support from both formal and informal sources. However, the stigmatised nature of the virus severely restricts the support available to many women.

Formal supports

Many sources of formal support, such as those from the Department of Community Services, or health services, were not accessible to some mothers because in seeking assistance, they placed other aspects of their lives at risk. This is largely because most women with hepatitis C are current or past injectors. As has been documented in Australia and overseas, mothers with drug use problems are often deterred from seeking assistance because doing so involves identifying themselves as drug-using mothers to the authorities.
In particular, mothers are concerned that authorities will remove their children from their custody, a pattern that has been found in Australia (Copeland, 1994; Swift and Copeland, 1999), the UK (Klee, 1998; Klee, 2002e; Powis et al., 2000; Taylor, 1993), the USA (Beckett, 1995; Murphy and Rosenbaum, 1999) and Canada (Rutman et al., 2000). This can have serious negative consequences, the risk of which must be considered in relation to the potential benefits they anticipate they will receive.

Mullings (2001) reported that women injectors experience difficulties in achieving legitimate social roles through a ‘narrowing of life’s options’ as a result of the labelling process involved in being identified as an injector. Similarly, Dawn demonstrated that it is not the deviant behaviour in itself which has social consequences, but being identified, through a social label, such as being a methadone client. In both this and the Mullings (2001) study, similar to Rosenbaum’s (1981) ‘reduced options’, as women become more engulfed in the drug world, the process of secondary deviance through social labelling is evident, creating further social marginalisation for women injectors as their access to conventional social roles becomes increasingly restricted over time.

As a key factor common in the majority of child deaths resulting from abuse and neglect (NSW Commission for Children and Young People, 2001), we can expect authorities to pay close attention to mothers with drug and alcohol problems. This is not of course to say that all mothers and fathers with a history of drug and alcohol problems are bad parents, but are identified as high risk and treated with suspicion. For the many parents who have drug and alcohol problems and believe they are good parents, this is very frustrating, and can make them feel discriminated against and in some cases, demonised, despite their efforts and abilities. Women such as Dawn, felt they have to prove their parenting abilities far more than other parents. As most parenting responsibilities fall onto the shoulders of
mothers, women in particular bear this responsibility, and the accompanying guilt when they perceive themselves to have failed to meet the mark. Being identified as an unfit mother is demoralizing and highly stigmatised, and fuels the social marginalisation of women with hepatitis C.

**Informal supports**

Most women with hepatitis C are current or past injectors. As such, they often lack good support networks, comprised of family and friends. The women in this sample reported that the problems surrounding their drug use had led them to sever ties with family and friends, or for their relationships to be severely harmed by it. For some women, their drug use is related to their poor social relationships in the past that have continued to cause them problems into the present (Bennet, 1995; Gil-Rivas, Fiorentine and Anglin, 1996; Paone, Chavkin, Willets, Friedmann et al., 1992). For example, it has been found that there is a high prevalence of past sexual abuse among female drug users, which may have contributed to their drug use. Because hepatitis C presents a range of physical, social and emotional problems, women living with the virus require more support, particularly in relation to motherhood, but unfortunately this is severely lacking for many. Jocelyn described how single parenthood had been difficult because she had not received any support from family, nor the father of her children as he died when her children were very young. Upon becoming become too sick to work being dependent upon state benefits, from which she had to buy her costly hepatitis C related medication, things had become very difficult.

The level of poverty you sink to, you know that you get so poor. And because in my case I do not have family here, so I am the only one of my family here in Australia, the rest is all still in Holland, and America and Canada whatever. There is nobody else in Australia. I’m a sole parent, always have been. So everything I made [financially] to sort of like get the kids higher than the
poverty level was through my own work. And you know I got very sick and then all that goes out of the window, so you know, you’re immediately back on the level of only a pension, and nobody else helping you. And really increased [costs] bits and pieces. Like I have 11 medications that I take in the mornings for this and that. It has to be paid, that’s extra you know. And luckily my kids are older, so yeah, it was hard on them, but not, you know, if they had been like small still and I would still have to physically look after them. You know that would be a lot harder, I don’t know how I would have handled that. 

**Jocelyn**

**Infection control**

When asked how hepatitis C affects motherhood, many women reported that they were constantly aware that they present an infection risk to their children, and as such had to be very careful to avoid any possibilities of them contracting hepatitis C. The fear of being the source of a childhood hepatitis C infection was a cause of great anxiety for many women, even though they perceived the risk of transmission to children through breastfeeding and household transmission to be very small. However, such a risk is magnified by stigma because it is considered socially unacceptable because of the deviant behaviour it is associated with. Within the contemporary ideology of motherhood, a mother is expected to do everything possible to maintain the wellbeing of her children. This is expected to be an ‘instinct’ that mothers naturally possess; a notion which is rejected by Nakano Glenn (1994) and Wearing (1984) and other feminists in favour of a socially constructed ideology of motherhood. In presenting a risk of hepatitis C infection to her children, although negligible and manageable, mothers with hepatitis C do not satisfy all the requirements of being the ‘perfect mother’. For this they felt guilty, as they are expected to by society. In this, they are very similar to women living with HIV, who are perceived as ‘vectors of disease’ to their children (Baylies, 2001; McDonald, 2002). Like other women who are considered to be inadequate mothers, such as teenage and disabled mothers, the women in this study defended their mothering abilities (Kirkman, Harrison, Hillier and Pyette, 2001).
The only changes I have made is to be extra careful in my household because I have got two children, so if something happened like there might be a blood. Like I was cooking the dinner and I cut myself or I might have been cutting up carrots, I would throw the whole lot out. Whereas previously I probably would have cleaned myself up and continued on cutting the carrots and throwing them in the saucepan. I am very confident of my mothering skills. I know I am a good mum. I wouldn’t say it [hepatitis C] had any influence on the children at all. It never had any affect on my ability to mother them or. The only thing with the hep C is you have to be extra, extra careful. Janice

There were some reports on the difficulties in preventing situations that might present a hepatitis C transmission risk. This was a source of concern for several mothers.

My daughter had grabbed mine [toothbrush] once, I think her dad had her tested [for hepatitis C] and she’s clean, but I just think he should go and get her tested again, and I hope he has because she did grab it, once or twice cause it’s an electric one, she’s fascinated by it. I didn’t even realize until one day, I found her and she was pressing the button on it, and I heard the button. Yeah, so that kind of thing has to be out of reach. And razors and things like that. Abby

It does worry me sometimes I have to say, that I perhaps should be more careful. I mean I’ll have something and he’ll want a taste of it and I’ll give it to him. And then I stop and think shit, no, I shouldn’t be feeding him from my spoon. Because maybe, they don’t really know, with all of that saliva, maybe with all of it he’ll get it from, I mean when he didn’t have it and all that sort of thing. Sarah

Managing the physical symptoms of hepatitis C and motherhood

Most women with hepatitis C do not experience permanent debilitating symptoms. Many do, however, experience some fluctuating symptoms of varying severity and nature. These symptoms may restrict a woman’s mothering abilities in that they may prevent her from being the constant presence and provider of their children’s every need, as is required in ‘intensive mothering’. Because of this, a woman with hepatitis C may be deemed selfish in having children, because she is unable to give them her all. Within the current ideology of
motherhood, as described by Wearing (1984), in order to provide the ‘intensive mothering’ that is so highly valued, mothers must give their ‘everything’ to their children. Those who do not give everything are considered to be bad mothers (Swigart, 1991).

Because most women in the sample did not experience regular severe hepatitis C symptoms, they reported that physically, their hepatitis C did not present great problems to their mothering abilities. Some women did, however, speak of the difficulties that arose on the occasions when they did have hepatitis C symptoms and they had to manage these as well as caring for their children.

I do take every day as it comes. Like if I’m feeling like shit in the morning, well you can guarantee I’ll be feeling worse by the afternoon. And you know, there are days where I’ll drop my son off at school and I’ve just got my daughter at home, and I’ll, she’s pretty good, you know she’ll just go off and play in her room or whatever, and I’ll spend the day on the couch. You know, days like that, and yeah, it’s pretty cool. But yeah, you know, it all just depends on how you feel in the morning. Kelly

Yeah and now with the hep C I’m just getting more tired and I’m finding I feel tired. I want to take my son out to do things, but I just don’t have the energy. Linda

Although Sarah had many advantages over most of the women interviewed, being happily married to a supportive man, having lots of friends and being financially very comfortable, she still found it difficult sometimes, indicating just how difficult it must be for those who are poor and do not have familial or other support.

All the women who worked for the drug users support organisation indicated that mothers who do experience symptoms, often in combination with malaise associated with drug use, can struggle in their role as mothers, largely because they have a lack of support when they
need it. The statement below is from a woman who worked for a drug user support organisation.

I think it makes their job really, really tough. Especially single women who don’t have a partner to lean on when they are not very well. I do get calls like that from women who are sick. Quite often they don’t realize they will be telling me all these things that are happen to them. I guess because we are trained, you know, you know straight away that’s the hepatitis C, that’s what’s the matter with you. But they don’t have a partner to you know, ‘can you watch the kids for an hour while I go and lie down?’ There are so many women out there who just don’t have anybody to help. You know, there are some women really suffering horrifically out there with the hepatitis C and all the related issues that they have got to deal with. And as I said before, I think you do have the services to be able to help these women but what we are doing wrong is we are not making them aware that they are there.

In reality, there are many women who have restrictive health problems who become mothers, yet these mothers are not perceived as negatively as women with stigmatised diseases such as hepatitis C or HIV/AIDS (McDonald, 2002). The way in which they became diseased is all-important in determining how they are perceived in relation to motherhood. If they are perceived to be to blame for their disease, particularly through association with deviant behaviours, such as IDU or being promiscuous, their ability to mother is questioned more seriously. Women whose mothering abilities are perceived to be restricted by their health are subject to judgement and a lack of support from both formal and informal sources. Mothers with disabilities, for example face many difficulties and moralistic questions regarding their ability to mother. If we compare the issues faced by women with disabilities with women with hepatitis C, there are several similarities, although there are also major differences. The issues faced by disabled women in childbearing and motherhood were described by Holland Baskin and Riggs (1988: p249) as ‘daunting and dispiriting’ and many of these problems were created by the attitudes of
others. Holland Baskin and Riggs (1988) reported disabled mothers to be ‘confronted with physical as well as psychological barriers in their daily lives’. Like women with hepatitis C, disabled women reported difficulties with medical professions in regard to their desire for children. Some doctors were reported to be reluctant to assist disabled women to have children, as has been documented for women with HIV (McDonald, 2002) because, it seems, they do not approve of them becoming mothers. This causes distress and anxiety as well as creating barriers to satisfying motherhood for these women, and reduces their opportunities to recreate their spoiled identities by becoming a good mother.

Disabled mothers reported that their responsibilities to their children provided them with ‘resolve to go on with their lives, despite pain, loneliness, or despair’ (Holland Baskin and Riggs, 1988: p251). Several women with hepatitis C in this study reported similar feelings; that their children provided them with a reason to not use drugs, and to take better care of themselves.

That was it [having children], that’s what gave me a routine and a responsibility. I could have either lost them or done the best I could. Veronica

Becoming a mother has the potential to improve the health and wellbeing of some women with hepatitis C, particularly those who have a drug dependency problem, as well as changing their social identity. However, we must also consider the effects, and potential effects of motherhood upon the women’s hepatitis C related health. For some of the women interviewed, this was a source of great concern, and contributed to their childbearing decisions. Several women, such as Theresa, reported feeling concerned about the effect that having children might have upon their hepatitis C related health, especially in relation to their childbearing decisions. Only a very small number of women made any kind
of reference to health problems they experienced because they have children. The women who did report an association between their poor health and their children, reported being tired because of the demands of motherhood combined with other demands made on their time. They did not believe this to be because they have hepatitis C, but it is in fact believed to be common amongst most contemporary mothers because of their demanding roles. None of the women reported that they believed having their children had resulted in the overall deterioration of their health.

Holland Baskin and Riggs (1988) discuss the question of the acceptability of a mother calling upon her children for help with tasks when they are struggling because of their disability. Generally, disabled women’s reports of their experience of having to receive assistance from their children were positive, causing few, if any, problems in their relationship with their children. Some disabled women believed the experience to have beneficial effects for their children’s self development and social skills. Both the disabled women in the Holland Baskin and Riggs (1988) study and the women with hepatitis C interviewed in this study reported that there are limits to what a mother can ask of her children and exceeding these limits can cause problems, as were also described by women in the present sample.

Because on family you can really dump [emotional and practical problems on them]. I have very good friends, you know, and they have really helped me, but you can’t put too much on your friendships, and you can’t put too much on your kids either, you know, because it is just too heavy. Jocelyn

Holland Baskin and Riggs (1988) also considered the problems associated with being ‘different’ to other mothers, and the social stigma involved in being disabled. This can be particularly problematic when children become teenagers and there is a great need to fit in
with those around them; which means not having any noticeable differences, such as a
mother with a disability. While this can present significant problems for some families, the
stigma associated with hepatitis C is of greater gravity in some respects and has an
everseous moral component. As such, the social issues associated with being a mother with
hepatitis C are likely to involve more severe social rejection and sanction than those
involved with disabled mothers.

**Employment**

Contemporary western women are also expected to have achievements outside the home,
usually in the form of employment, in addition to providing some degree of ‘intensive
mothering’ to their children (Brown, Lumley, Small and Astbury, 1994), especially if they
are single mothers who cannot depend on a male partner's income (Lewis, 1991). This is
extremely demanding, and for women who experience hepatitis C symptoms, may prove
impossible. However, this has other implications also, as being unable to work outside the
home, as many contemporary mothers do[^38] also means a lower income. For single mothers
this may mean a greater likelihood of becoming dependent upon state benefits, which is
socially stigmatised within itself. Janice was in the minority of women in the sample, as she
had two children and worked full time. Janice reported that she did not experience any
hepatitis C symptoms. She did feel very tired sometimes, but this she pointed out, was
more likely to be because she was working full time and caring for her children, which is
very demanding.

[^38]: In 2000 63 per cent of women with an employed partner and dependent children were engaged in
employment. However, 51 per cent of lone parents were employed, and most (86 per cent) of these were
women. (Australian Bureau of Statistics, 2000). Mothers' employment often depends upon the age of her
youngest child, as well as whether or not she has a partner with whom to share the parenting responsibilities.
Many mothers with young children are restricted in the paid employment they are able to do because of the
demands of lone parenthood.
Yeah, you do get tired a lot but you know, I guess I’ve never put it down to the hep C. I put it down to the fact that I have got a very busy lifestyle ‘cos I’m a working mum and I guess I never ever thought of that. Janice

Veronica had recently experienced difficulties in obtaining employment. She felt that it is important to be employed, for her self-esteem in addition to providing good mothering for her children. She felt she would be a better mother if she feels better about herself.

I’d like to know that I am willing to go out to work and not to bludge on the dole, which I know I am. And I would have self-respect that way, maintaining that spirit at home and give it to the kids for when they go to make their homes. I don’t want them to have to go through anything like I went through [as a sex worker with a drug dependency] as an indecent member of society and I want their generation to be good, better than me and why I had to be that way. Veronica

Several authors (Cannold, 2000; Swigart, 1991, for example) have reported that many women anticipated a conflict between ‘good mothering’ and their employment, in which mothers feel guilty for not providing ‘intensive mothering’ in order to pursue their career, or simply maintain their earning capacity. Women in this sample also anticipated such problems, but also have to contend with the possibility of hepatitis C related poor health also impacting upon their abilities to engage in paid work as well as perform the endless tasks associated with motherhood.

Why are women with hepatitis C considered to be inadequate or bad mothers?

The ideology of motherhood (Wearing, 1984), or the canonical narrative of motherhood as Kirkman et al (2001) describe, portrays mothers as self-sacrificing, caring, and virtuous,
with character traits of nurturance and lack of competitiveness (Boyd, 1999; Klee, 2002a; Klee, 2002b; Lawler, 1996). All of these characteristics are conducive to good mothering based upon Wearing’s suggested tenets of motherhood (Wearing, 1984: p33). Because of the associated IDU, society presumes women with hepatitis C to be morally flawed, self-indulgent, reckless and dangerous. These traits are particularly conflicting with the ideal characteristics of ‘good mothers’ required to fulfil the four key tenets of motherhood. The interview data indicate that women with hepatitis C are assumed to possess these undesirable characteristics associated with the image of the stereotypical ‘junkie’. The women also directly related these characteristics to their evaluation of their suitability to mother, or more often, to others’ assessments of their ability to mother.

I think it’s just been drummed into their heads, your mothers a junkie. She can’t bring anything home to you, stuff like that. It weighs on their heads. It weighs on mine too. Amy

The women described the way that others assumed they are unsuitable for motherhood because they are assumed to possess traits such as untrustworthiness, immaturity, promiscuity, irresponsibleness and inadequacy, as Taylor (1993) reported. These characteristics are all widely considered to be unsuitable for motherhood. Because of the strong link between hepatitis C and drug use, women with hepatitis C are assumed to have the same characteristics and thus to be unfit mothers.

**The values involved in ‘good mothering’**

The interview data indicate that as Lewis et al (1995) reported among drug-using pregnant women, women with hepatitis C hold the same values as society regarding motherhood. Women with hepatitis C, like many other women with the charge of being an unfit mother, are faced with circumstances that make achieving ‘good mothering’ difficult. In particular,
those women who are current or past injectors have problems beyond their control that may impact upon their mothering. While most women in this study reported that it is generally undesirable for a mother to be injecting drugs, or be on a methadone program, they were also strong in their defence of their mothering skills, despite their IDU or remaining on a methadone program.

There is a growing body of evidence that the environment of children of parents who use illicit drugs, or have used illicit drugs in the past, is potentially very harmful. Most of this evidence is focussed upon drug-using mothers, rather than fathers, probably because parenting remains primarily, the role of women, rather than men (Birns and Ben-Ner, 1988; Cannold, 2000; de Kanter, 1988; Everingham, 1994; Gross, 1998; Hird and Abshoff, 2001; Lawler, 1996; Lewis, 1991; Nakano Glenn, 1994). Children of drug-using parents are assumed to expose their children to direct harms, such as access to contaminated drug-using paraphernalia and illicit substances, as well as less direct harms through poor role models and exposure to drug-dealing and violent behaviour. Women with hepatitis C, because of their associated IDU, are assumed to bring their children up in this damaging environment, as discussed in the literature review. Even mothers who no longer inject are assumed to provide inadequate mothering because they are assumed to possess poor morals and to be ‘polluted’ socially as well as biologically.

Many mothers, such as Janice, inject illicit drugs, but report that their children are in no way exposed to any of the distressing experiences and poor influences as described above. Janice explained that maternal drug use is a matter of degree, and demonstrated by comparing her IDU with mothers who drink alcohol. Because of its illegal status and pervasive stereotypes, IDU is perceived to equate drug dependence and a lack of control.
I make the analogy of you know, women who go out and have a few drinks it’s more of a social thing, at my home there is no drug paraphernalia lying around or my children have never been exposed to my drug use. Just the same as if I was a drinker instead of a drug user I wouldn’t expose them. I wouldn’t be lying around drunk. It’s something they don’t know about, it’s a very private part of my life that you know, doesn’t affect, but it certainly never affects my ability to, to being a good mother. *Janice*

There were differences in the way in which the women dealt with the issues of hepatitis C and drug use in relation to motherhood. Some women, such as Janice, believed they had managed to completely shelter their children from any knowledge of hepatitis C or drug use. Other mothers, however, such as Sharon and Rebecca, chose another approach in which they perceived it to be beneficial to be completely open with their children so that they understand the problems their mothers face.

I don’t keep thing from her [daughter] but I’d rather her find out things from me than find out from somebody else. So I have always been honest with her. Yeah I think people too, like myself, think women should be more, if they have children a little bit older, should be honest with their children. Because I think if their mum is sick, the child wants to know why their mum is sick, and if the child does not know… *Sharon*

Several women reported that they felt guilty about using drugs, particularly because it had led to their hepatitis C infections, which presented risks to their children, as described by Klee et al (2002). That the women indicated that they feel guilty indicates that they share the same values regarding motherhood as wider society. They subscribe to the ideology of motherhood. If they did not, then they would not experience this sense of guilt.
Having children removed from custody

Seven of the women who had existing children reported that their children were in the custody of others. Five of these women reported having their children removed from their custody without their agreement, whilst two women had entered into the agreement voluntarily, making arrangements with family and the fathers of their children. Taylor (1993) also found that when women were unable to cope with the responsibilities of motherhood because of drug use, they made arrangement for the care of their children with other trusted people. Again, this demonstrates that drug-using women share many of the same values as the general public regarding motherhood.

For a woman to have her children removed from her custody is devastating, as was evident in the personal accounts of the women interviewed. There was an enormous sense of loss of their children but there was also a changed sense of identity because they were considered to be harmful to their children. They internalised the label of being a ‘bad mother’. Some of these women were working at regaining custody of their children, whilst others seem resigned to the fact that they will be cared for by other people.

The main reasons for them losing custody of their children were IDU and related issues, such as poverty and criminal behaviour, and living with abusive men. All of the women who had lost or surrendered custody of their children had current or past drug dependency problems. Hepatitis C was reported to be a contributing factor towards the custody loss, but only in relation to IDU. Hepatitis C, as a social label, was used to discount the women and used as an indicator that they are unfit mothers; it was used to demonstrate that not only do they inject drugs but they are also diseased as a result of doing so. As such, they
represent several threats to their children. There were no reports of hepatitis C being used to indicate that they may not be able to fulfil the practical tasks involved in motherhood, relating to their physical fitness. Rather, hepatitis C was used as a marker of deviance, which is an indicator that the women were unfit mothers and a potential infection risk.

Most of the women who had their children removed from their custody reported that they would like to have at least one more child. These women perceived another child as a new opportunity to be a good mother. Most women who had experienced having their children forcibly removed from their custody believed it would be very difficult to regain custody, as also reported by Taylor (1993). For some women, it seemed that having another child was perceived to be a more viable alternative than attempting to regain custody of children that had been forcibly removed from their care. They were very fearful of the risk of future children also being removed from their care but expressed determination to prevent this from happening. A new baby would allow them to reinvent themselves, which regaining custody of their existing children does not necessarily do. Existing children are a consistent indicator of their spoiled social identity through drug use and losing custody of their children.

Having their children removed from their custody can cause women’s drug dependence to worsen as they attempt to deal with their anguish and guilt. Taylor (1993; 1998) reported that for some women, having their children removed from their custody acted as a motivation to stop or reduce their drug use. For other women, however, the distress this causes leads them into further drug use. The women in the present sample reported both of these effects. For Gemma, having her daughter in State care acted as an incentive to cease drug use in order to try to regain custody.
I wanna do my higher school certificate and hopefully in the long run I want to earn my own money. Get my baby back. I can have her back as soon as I feel ready to take her back. They were like the rules on the form. I can’t get her back until I stop using, get back into the workforce, have a proper home you know like with a garden and stuff like she can play in and … Gemma

Summary: The meaning of motherhood for women living with hepatitis C

As Janice highlighted, the extent to which hepatitis C influences the lived experience of motherhood is a matter of degree. The issue is not black and white, there are many shades of grey. Just because a woman is a current or past injector, of which hepatitis C is an indicator, does not equate with inadequate or inappropriate mothering. Nor does a woman having hepatitis C, as an infectious disease, mean that she represents a health threat to her children. A range of factors influence the degree to which hepatitis C can influence a woman’s ability to meet the requisites of the ideology of motherhood. The age, race, other health problems, degree of drug use, education levels, and employment status, among other factors, may influence the degree to which hepatitis C impacts upon a woman’s ability to mother well. The nature of hepatitis C makes prognosis very difficult. Most women with hepatitis C do not know if they will be among the small proportion of people with hepatitis C who develop cirrhosis of the liver, liver cancer, or need a liver transplant, and for a very small proportion, die from hepatitis C. Nor do women with hepatitis C know when, if at all, they will begin to experience debilitating symptoms. As a mother this is a source of anxiety because of their responsibilities to their children. They are concerned they will not be able to perform all the tasks required to mother their children well and fear they may die before their children become adults.
The supports a mother living with hepatitis C has available to her in times of need, such as when she experiences hepatitis C symptoms, are crucial. Emotionally and physically, the problems having hepatitis C create for motherhood mean that women living with the virus need more support. Because of the stigmatised nature of the virus, support is exactly what is not there for many women with hepatitis C.

The data indicate that motherhood remains central to the identity of women. For those women who have decided to remain childless, they are defined as non-mothers. Whether or not a woman is a mother, and whether she is a good mother, remains fundamental to women’s social identity. That hepatitis C may prevent some women from becoming mothers has the potential to make a huge impact upon their social identity, which is usually negative. Because hepatitis C may prevent some women from having children, or significantly contribute towards childlessness, hepatitis C may contribute to further social marginalisation and even exclusion among a group already significantly socioeconomically disadvantaged.

Recent decades have witnessed significant social changes in which women have more choice about when and whether to have children, and how many children. Childlessness has become more common and increasingly socially acceptable, but the women who are choosing to remain childless are generally of higher SES, and as such usually have other legitimate social roles. For women who have low levels of education and who do not have a career, there are fewer legitimate roles available to them. For these women, motherhood remains the primary source of achieving social status. Most women with hepatitis C are of lower SES, which is associated with IDU. As such, we can expect these women to have fewer choices of legitimate social roles outside of motherhood. Because their health and social status conflicts with the ideology of motherhood, their access to this role may also be
restricted, and as such they are more likely to experience social marginalisation. Those women who do have alternative social roles to motherhood are less likely to experience such marginalisation as a result of remaining childless. That women with hepatitis C in this study who had chosen to remain childless were largely of higher SES may indicate that women of lower SES are less likely to remain childfree because they have fewer choices and despite several difficulties and risks, do not compromise on their goal to become a mother and achieve a more respectable social status. Women are having children in more diverse social contexts than ever before and this is becoming increasingly socially acceptable (McDonald, 1998), however, the increased choices available to most women in western societies are not available to women with hepatitis C, who are still very much restrained by the traditional ideology of motherhood because of their highly stigmatised social status.

Following on from the previous two chapters on the social experience of hepatitis C and the effects of hepatitis C on childbearing decisions, this chapter has discussed the ways in which living with hepatitis C affects experiences and expectations of motherhood. The following, and final chapter will bring all of these issues together and provide some suggestions for policy direction based upon these findings.
Section 4: Discussion and Conclusions

In this section there is only one chapter which brings together all the findings of the thesis as reported in section 3, in relation to existing literature. Based upon these conclusions, recommendations are made regarding policy change and future research directions.
Chapter 11: Discussion and Conclusions

The main aim of this thesis was to develop a detailed understanding of the meanings given to the experiences of childbearing and motherhood among women with hepatitis C, and to explore the social processes through which they are developed. In particular, the thesis has explored the ways in which hepatitis C influences social identity, and how women living with the virus attempt to manage their social identity. The ways that hepatitis C can affect motherhood through childbearing decisions, directly and indirectly, have been investigated in detail in order to explore the meanings and processes of motherhood. Additionally, the barriers that hepatitis C may present to successful motherhood have been investigated.

Each chapter of the thesis has explored the childbearing and motherhood experiences of women with hepatitis C in relation to the theories of deviance and stigma and the social construction of motherhood. This has been examined in the context of extant literature on female IDU and the gendered experience of living with hepatitis C.

This chapter will discuss the conclusions of each of the findings chapters in relation to the theories covered in the literature review. Based upon these findings, policy recommendations will be made in order to address some of the problems experienced by women with hepatitis C highlighted in the thesis. Future directions for research will be suggested throughout.

The following discussion highlights the ways in which hepatitis C can impact upon the social identity of women, from several different theoretical approaches. These are: stigmatised identities; secondary deviance through the process of social labelling; the sick
role; and the medicalisation process. Each of these ways in which hepatitis C can impact upon women’s identities is assessed in relation to the social construction of motherhood.

**Stigmatisation**

People living with hepatitis C have been shown to be highly stigmatised throughout extant literature (Faye and Irurita, 2003; Gifford et al., 2003; Hopwood and Southgate, 2003; Puplick, 2001), and this was clearly demonstrated throughout the interview data, and is evident in all of the findings chapters. This stigmatisation is largely the result of the close association of the virus with IDU, but also because it is an infectious, potentially fatal virus, about which there is little medical or social understanding. Hepatitis C is an indicator of deviant behaviour; IDU. It is also an indicator of a highly deviant identity, which implies a process of social labelling. For an individual to have a deviant identity, rather than merely exhibit deviant behaviour, implies that a deviant label has been applied to that individual and the label has been incorporated into their social identity (the social category into which an individual is assumed to fit and traits they are assumed to possess), and concept of self (how an individual perceives themselves in relation to others).

The stigma of hepatitis C allows society to identify individuals and groups who represent some form of danger (to their own children in particular). In this case the danger is hepatitis C infection or moral pollution. Hepatitis C indicates pollution; biologically because it is a virus; and socially because of the deviant behaviour with which it is associated, and the assumed auxiliary traits people living with hepatitis C are assumed to possess and the contact they are assumed to have had with other deviants. Once people are identified as ‘others’ (Becker, 1963), society is more able to maintain distance from them and apply formal and informal forms of social control. In identifying people with hepatitis
C as ‘others’, society is more able to distance themselves from the people living with the
virus by restricting their access, through discrimination, to social positions such as
employment, or motherhood, for example. Link (2001) claimed that the stigmatised
individual becomes the thing they are so labelled, rather than possessing that particular
attribute, as reported by several women in this study. Hepatitis C is not only a virological
phenomenon, but is also socially symbolic; it represents moral danger as well as an
infection risk.

The virological threat women with hepatitis C may pose to their children is seen through
the filter of stigma, staining it with moral pollution, thus making it appear less acceptable.
Once a deviant behaviour becomes known to others, it is often assumed that the incident
or particular behaviour that has been discovered is actually only a small part of a greater
deviant identity; the deviance is magnified as it is often assumed that there is further
deviance (Goode, 1978). There exists a strong association between health and morality, in
which illness may be perceived as a form of deviance, or as a cause of illness (divine
retribution for example), (Balshem, Oxman, van Rooyen and Girod, 1992; Brandt, 1991;
Conrad and Schneider, 1980; Parsons, 1951; Petersen and Lupton, 1996), especially in
relation to childbearing (Bedimo et al., 1998; Quinton, 1991; Zaner, 1982). Viruses
contracted through deviant or socially undesirable behaviour, such as hepatitis C,
HIV/AIDS and sexually transmitted infections, demonstrate this association. Lupton
(1995; 1999) highlights, however, that even eating the wrong type of foods or not
exercising which may lead to poor health, also demonstrate an association between living a
‘good’ life and a ‘bad’ life, or at the very least, being held to blame for any resultant disease.

Hepatitis C represents a moral threat because it is closely associated with a highly deviant
identity; the ‘junkie’. ‘Junkies’ pose a number of threats to society, in the form of the
criminal behaviour with which they are associated, and the threat of disease they pose (HIV/AIDS and hepatitis C in particular), as they are perceived as a reservoir of disease and are believed to exhibit behaviour that poses a threat of infection to others. In particular, ‘junkies’ are perceived to pose a threat of abuse or neglect to their children.

It has been shown that the stigma associated with hepatitis C is worse for women than for men, and that women experience more hepatitis C related discrimination (Day et al., 2004; Day et al., 2003). There are several causes for this greater level of stigmatisation. Firstly, the IDU with which the virus is closely associated is perceived to be particularly inappropriate because the behaviours, personalities and lifestyle of women injectors are perceived to be in conflict with the role of women as carer; principally wife and mother. Secondly, the physiological impacts of hepatitis C may limit women’s abilities as a wife and mother. This stigma is closely related to gendered social roles; Temple-Smith et al (2003) showed that experiences of hepatitis C were very different according to gender and that these differences were largely explained by gendered social roles. Just as women’s experiences of hepatitis C are related to their primary social roles as mother and carer, men’s experiences of hepatitis C are related to their social role of ‘breadwinner’. The degree to which women experience greater levels of stigma and discrimination than men are likely to be explained by the auxiliary traits associated with hepatitis C being not only practically problematic in terms of mothering because of physiological limitations, but also morally, because women with hepatitis C are presumed to be morally polluted. Mothers in particular are expected to be of high moral standing. The effects of stigmatisation can be severe. The many negative consequences of stigmatisation have been well documented throughout this thesis, all of which were reported by the women in this study and include: low self-esteem; shame; isolation; rejection; discrimination; financial insecurity; and anxiety.
In section three, it has been shown that seeking medical care and social support can involve a great deal of risk to women with hepatitis C, and can call into question custody of their children. In seeking help for hepatitis C, mothers or potential mothers disclose their identity as a current or past injector, and in the case of women who have never injected, they must deal with assumptions that they are current or past injectors. They must then deal with discrimination based upon the stigma of having hepatitis C, and in most cases, being a current or past injector. Of particular concern is the threat of the Department of Community Services (DoCS) becoming involved and potentially threatening the removal of children from their custody because of maternal drug use, or even being on a methadone program; because these women are assumed to be neglectful or abusive mothers. This represents a major deterrent to health care and support seeking for women with hepatitis C who are often in great need, and may lead to further deviance. Some discrimination may be due to a perceived threat of infection, but based upon existing literature (Day et al., 2004; Day et al., 2003) and the interview data, it would seem that most hepatitis C related discrimination is actually because of the close association of the virus with IDU.

The interview data confirmed that people of higher SES are more able to defend themselves against negative social labelling and the process of secondary deviance. Women of higher SES in this sample reported experiencing stigma because of their hepatitis C and associated IDU, but the effects of this (discrimination) were not as severe as for the women of lower SES. This was because they possessed other positive social characteristics that, although tainted by their stigmatised identity, conflicted with the stereotypical traits which women with hepatitis C and injectors are assumed to possess. These women were also less likely to be identified as deviant in the first place because their positive social characteristics conflict with the deviant identity.
Women of higher SES in this sample were more likely to have a stronger support network of formal and informal supports that help to reduce the impact of any negative social labelling, than the women of lower SES. This may be because lower SES was associated with IDU, as indicated in most samples of injectors and as such, the never-injectors had more support options available. It is possible that in being a current or past injector some potential sources of support are restricted. For example, some women reported that their drug use had resulted in their relationship with their family dissolving, or that they felt they were unable to go to a medical professional for support because they feared discrimination. Some restrictions on sources of support to injectors may be the result of the process of secondary deviance, whereby legitimate sources of support are withheld because of their deviant identity, as has been described for injectors by Hunt and Derricott (2001). Additionally, women of higher SES possessed more skills to be able to defend themselves from such processes. For example, more educated women were more able to articulate their demands of medical professionals and assert their knowledge of their rights.

Women who had never injected did not carry with them the burden of the injector label. Although they may be assumed by some people to have injected, especially if they were of low SES, they did not have the lived experience of injecting or being labelled as an injector, and so had not embodied the injector identity. Women of higher SES were more often the women who reported never having injected, but there were also current injectors who were of higher SES than most of the other women.

Women of lower SES who were socially marginalised were often current injectors, and possessed few positive social traits which may have aided them in defence of their social identity. Women who were current or past injectors had embodied the injector or ‘junkie’ social label over time, which reduced their ability to be able to defend themselves against
the negative effects of living with a stigmatised virus such as hepatitis C. Injectors are often poor, unemployed and have low levels of education, and as IDU is the primary source of hepatitis C infection, most women with hepatitis C possess the same or similar characteristics. They often have restricted access to information which may arm them in order to address medical professionals more confidently. Their multiple negative social labels are compounded by hepatitis C.

Through the process of secondary deviance, as described by Lemert (1951), someone who exhibits deviant behaviour is socially labelled, and then goes through a process by which legitimate social roles become increasingly restricted, forcing them into further deviant behaviour, reinforcing the deviant label. As this process progresses, the so-labelled deviant comes to define themselves as deviant and as an ‘other’, and begin to manage their deviant identity, which by this stage has often become their master status.

There was evidence of the process of secondary deviance, or social labelling, having occurred in this sample of women with hepatitis C. In carrying the stigma of hepatitis C, women were prevented from occupying some social roles, including employment and caring for children, or being denied services, or receiving discriminatory service. The process that they described is closely associated with the career of narrowing options for women heroin users as described by Rosenbaum (1981) and Mullings et al (2001), because so many of them were current or past injectors. Hepatitis C can create and reinforce stigma by creating dependence upon state benefits as those living with the virus are unable to earn an income through paid work through discrimination and incapacitation as a result of symptoms. Having hepatitis C strengthens the deviant status, and fuels the process of secondary deviance.
A spoiled identity is an identity to which a discrediting label (stigma) has been applied (Goffman, 1963). As a deviant status is often a master status, hepatitis C is central to the social identity of many women living with hepatitis C. For those women who have gone through the process of secondary deviance because of IDU, hepatitis C is likely to play a greater part in defining their social identity, as each additional layer of stigma and deviant characteristics is added into the process.

In many cases, the IDU, current or past, is a bigger issue than the hepatitis C itself. Hepatitis C adds another layer of stigma to the spoiled identity of being an injector. Hepatitis C not only indicates IDU, but also represents part of the social labelling process as it reinforces the stereotype of the ‘diseased junkie’. Any suffering as a result of hepatitis C is often perceived to be the fault of the person living with the virus, because of the IDU with which it is associated. As such, responsibility for the wellbeing of people with hepatitis C is transferred to those living with the virus.

The sick role

The sick role as described by Parsons (1951) offers a model that demonstrates the ways that living with illness affects social identity, by assessing the way that it affects social roles. However, Parsons’ (1951) concept of the sick role does not accommodate hepatitis C well on several counts. Firstly, one of the conditions of the sick role is that the person with the illness is not to blame for their condition; women with hepatitis C are often held to blame for their infection because it is usually acquired through IDU; behaviour which is assumed to be a choice. Secondly, the sick role does not apply well to chronic conditions such as hepatitis C. When Parson’s conceptualised the sick role, it was acute conditions he had in mind that only occur for discrete periods of time. Thirdly, the fluctuating nature of
hepatitis C symptoms does not permit a well defined social role because roles are
determined by ability to perform tasks; fluctuating symptoms often mean that an
individual’s capacity to perform particular tasks can be highly variable. Fourthly, it is a
condition of the sick role that sick persons make efforts to return to good health as soon as
possible, but often people with hepatitis C may continue the behaviour (injecting) that had
led to the infection in the first place and which could be harmful to their hepatitis C related
health. Fifth, it is a condition of the sick role that sick persons should be under the care
and supervision of a medical professional. Treatments for hepatitis C remain limited in
success and availability. Additionally, medical professionals often present a threat to
women with hepatitis C in the form of discrimination.

This study demonstrates that the fundamental concept of the sick role remains relevant to
women with hepatitis C, in that sickness is assessed in terms of its impact on an individual’s
capacity to perform their regular daily activities, or social role. It is, however, inadequate in
fully explaining the social process at work in defining the social role and identity of women
with hepatitis C. The women in this study assessed the impact that hepatitis C had upon
their lives in terms of the degree to which it prevented them from performing their normal
daily activities. Motherhood remains the primary social role for many women, especially
women of lower SES (as most women with hepatitis C are). The degree to which hepatitis
C impacted upon their lives and social identity was related to the degree to which hepatitis
C affected their ability to bear children and mother. While hepatitis C undoubtedly creates
some physiological problems for some women, overall, the social and psychological impact
upon social identity is far greater.

In addition to the lack of clarity surrounding the sick role, the symptomology of hepatitis C
is unclear. Hepatitis C symptoms are easily confused with malaise associated with drug use,
methadone use, and generally being run down or other viral infections such as flu. Consequently, there is a lack of meaning associated with hepatitis C symptoms, which creates confusion regarding the effects that symptoms have upon social identity. Further, the poorly defined natural history creates enormous uncertainty in the lives of women living with the virus. As a result, the social role of women with hepatitis C is not well defined, and impacts negatively upon their social identity.

Treatment of hepatitis C was reported to represent the possibility of reconstructing the social identity of past injectors. By ridding themselves of the ‘legacy’ of their injecting career, which hepatitis C represents, and of the restrictions that hepatitis C places upon their lifestyle, in terms of social drinking for example, some women believed they could regain the social identity they had before they were diagnosed with hepatitis C. However, this would not be possible for those women who had become engulfed in their deviant role (as described by Rosenbaum (1981)) and who had gone through the process of secondary deviance; the social identity of these women is too spoiled to be able to redefine in this way. The process of secondary deviance, which drives them into further deviance as legitimate means of living are closed off to them, means that even if they manage to shed one deviant identity, they still possess many more characteristics that indicate their deviance. Their deviant identity remains their master status.

**Medicalisation**

The process of medicalisation among people with hepatitis C, as described by Hopwood and Southgate (2003) and Faye and Irurita (2003) was evident among the women in this study (chapter eight). Several women reported a changed sense of self as a result of the medical definition of their condition. The hepatitis C antibody test, that is used as an
indicator of hepatitis C infection, for which all the women in this study had tested positive, represents the beginning of this process. Faye and Irurita (2003), however, reported that although the initial diagnosis causes feelings of being condemned, over time, people diagnosed with hepatitis C come to integrate this into their social identity, and accept the ways that living with the virus will affect their lives. The women in this study reported adapting their lifestyles because they have hepatitis C, and in doing so recreated their social identity. Often these lifestyle changes included making ‘healthy’, ‘good’ changes, such as exercising, or eating fruit and vegetables, as well as stopping or reducing drinking or drug use. The language the women used to describe these changes (for example, eating ‘good’ food, doing the ‘right’ thing) demonstrated a moral component to these changes, reinforcing the moral understanding of health and illness. The clinical markers used to assess and monitor hepatitis C related health represent further stages of the medicalisation process. Usually the consequences of the medicalisation process are negative (Hopwood and Southgate, 2003). There was, however, some demonstrated resistance to the process, by avoiding the clinical tests and medical professionals who initiate and continue such a process. Several women reported that they consciously avoided clinical tests for hepatitis C in order to avoid the tests redefining their social identity and sense of self.

**Mothering and the female identity**

Motherhood remains central to the identity of most women in contemporary industrialised society, although there now exist more choices for many women than ever before. Educated women, who are often white and non-religious (Cannold, 2000; Lievore, 2001; Marshall, 1993; Morrell, 1993), often have alternative legitimate social roles to motherhood, which they may choose instead of motherhood, or combine in some way with mothering. The women in this sample who had decided to remain childfree, with the exception of one
woman, all had alternative legitimate social roles in the form of a career. The one childfree woman who did not have a legitimate alternative social role reported the barriers to her becoming a mother and to being a good mother to be insurmountable. For marginalised women such as her, the effects of hepatitis C can be huge and work to ensure that she remains on the margins of society. For women of lower SES, who have low levels of education, low incomes and who are religious, however, motherhood remains the only means of establishing social status as a legitimate adult woman, as was found to be the case for women living with HIV (Bedimo et al., 1998; McDonald, 2002) and those identified as at high risk of having a child with sickle cell disease (Hill, 1994). For both of these types of women there were considerable health and socioeconomic risks to both the mothers and babies. These women demonstrate the importance of the role of motherhood to the female identity, as they are willing to risk so much in order to avoid remaining a non-mother. Hepatitis C presents less risk to both mother and child than either HIV or sickle cell disease and so in light of the importance of motherhood for such women, it is unlikely that hepatitis C will prevent them from having children. However, as has been demonstrated in this thesis, hepatitis C may affect the timing and parity of children. The majority of Australian women living with hepatitis C are of lower SES, as demonstrated in WLHC sample (Gifford et al., 2003). Consequently, we can expect the role of motherhood to remain pivotal in shaping the social identity of women with hepatitis C, as demonstrated by women in this sample.

For some women of higher SES, motherhood remains central to their identity, even though they had other legitimate social roles open to them. For these women, their other social roles were perceived as peripheral (chapter ten). This indicates that while there are more choices than ever before for many women in industrialised societies, motherhood remains the primary social role for most women. However, there is also a temporal aspect
to this. While many mothers are now permitted, and some are expected, to hold social roles other than motherhood, there are specific points during the life course where other roles are expected, and then other times where they are expected to give these up to take on the role of motherhood.

However, women with hepatitis C have a ‘spoiled identity’ because of the stigma associated with hepatitis C. The characteristics that they possess, and are assumed to possess, are deemed inappropriate for motherhood according to the current ideology of motherhood, as described by Wearing (1984) and others. Although motherhood remains the only means of establishing a legitimate female identity for many women with hepatitis C, having hepatitis C creates barriers to achieving ‘good mothering’; for example, the risks of vertical transmission are perceived to be too high by some members of society, or they may have reduced access to support services they need because of stigma and discrimination, or even the threat of losing custody of their children, as demonstrated in the data. Like other women labelled ‘bad mothers’, mothers with hepatitis C ‘attempt to construct a positive maternal identity whilst negotiating for effective help from welfare agencies’ (Croghan and Meiell, 1998: p445).

Conclusions

Hepatitis C has been shown to influence childbearing decisions of some women both directly, by creating a risk of vertical transmission of hepatitis C or posing serious future health concerns in relation to the ability to mother; and indirectly, by impacting upon the many factors that influence most childbearing decisions in industrialised societies, such as age and financial security.
The risk of vertical transmission, is generally considered to be low or very low in terms of the odds of it occurring (about six per cent), and moderate in terms of the consequences of an adverse outcome (childhood hepatitis C is thought to be milder and more likely to be asymptomatic than in adults). In relation to the risk of other infant health complications and congenital malformations, vertical transmission of hepatitis C does not appear to represent a large risk. The considerable uncertainties that remain in estimating the risk of vertical transmission and the natural history of childhood hepatitis C make any risk assessment very difficult. The incredible uncertainty involved in individual prognoses adds to this conundrum.

Some of the women in this sample, however, considered the risk of vertical transmission to be very worrisome and for it to play a significant factor in their childbearing decisions. This may be because the risk of vertical transmission of hepatitis C is stained with the stigma associated with the virus, which is an indicator of moral pollution, leading to feelings of guilt. In having hepatitis C these women are already morally questionable. Having a child and posing the threat of infection to them leads to further suspicion and a more deviant identity.

The majority of women with hepatitis C are current or past injectors, or are assumed to be. Although IDU is also deviant among men, it is perceived as a masculine behaviour, and so is considered more deviant among women. The auxiliary traits associated with IDU conflict with feminine norms, particularly regarding their primary social role as a mother. This suggests that women who inject do not share social norms and values. The data in this study and in other studies of drug-using women (Lewis et al., 1995; Rosenbaum, 1981) demonstrate that women injectors do in fact share the same values as society regarding
drug use and motherhood. They are, however, less able to achieve these ideals for many reasons, and as a result experience feelings of guilt and shame.

Motherhood is a socially sanctioned role for most women, although there do exist constraints that define the conditions under which motherhood is ideal (Lawler, 1996). This study supports that childbearing, the process by which the status of mother is achieved, creates a change in the social identity of women, which can be viewed from a negative perspective, in that upon becoming a mother, a woman is stripped of all her other social identities and is defined only in terms of her role as a mother. For women with spoiled (stigmatised) identities, being able to shed some of their negative social identities would represent a positive change. However, stigmatised identities are often permanent, depending on the severity of the deviance with which they are associated. Although women with hepatitis C who are past injectors may be able recreate their social identity to some degree, their spoiled identity may remain their master status. Those who continue to inject, or even remain on a methadone programme as a mother, are subject to further scrutiny from authorities and the general population (depending upon the visibility of injecting or being on methadone), and are exposed to being labelled as an abusive, neglectful or simply inappropriate mother. Such labelling restricts the resources, particularly sources of support, available to them to assist them in becoming a ‘good mother’.

The situation is different for women who have never injected. Although they may be suspected of being a current or past injector, because in fact they are not, they have not embodied the label and all its meanings into their self-identity. Additionally, because they are not injectors, they are less likely to have experienced rejection and withdrawal of formal and informal sources of support. Hence their ability to be a ‘good mother’ is enhanced by the supports that remain open to them that are often not available to women who are
current or past injectors. Mothers with hepatitis C who had never injected drugs experienced stigmatisation, as did the patients in the Zickmund et al (2003) study, though not for the all of the same reasons or to the same extent. The stigma of women with non-IDU acquired hepatitis C is less likely to be associated with deviance; more likely it will be because hepatitis C is infectious, and potentially debilitating and fatal. That hepatitis C is inadequately understood results in poorly defined meanings and social roles for those living with the virus.

Throughout the thesis it has been demonstrated that the source of hepatitis C infection shapes social identity. The meanings given to the virus are shaped by the behaviours associated with acquisition of the virus, rather than the biological effects of the virus. Other viruses, such as HIV/AIDS are also associated with moral judgement about particular behaviours. Lawless et al (1996) found that in becoming ‘diseased’, women with HIV had failed in their role as a woman, as carers and as mothers. Women with hepatitis C occupy a similar position to women with HIV in this respect.

The many ways in which hepatitis C can impact upon the social identity of women from several different theoretical perspectives has been demonstrated throughout this thesis. Motherhood is pivotal to the female identity. For many women, including those with hepatitis C, motherhood is perceived as a way to recreate their social identity. Women with hepatitis C, for whom this process of identity reconstruction is of great significance, however, carry with them the stigma of hepatitis C which restricts their ability to recreate a legitimate social identity through motherhood. Because they are viewed with suspicion, women with hepatitis C who have children are subject to more surveillance and social controls than other women and risk being labelled as a bad or unfit mother. For most, however, the risk of remaining a non-mother presents greater losses.
Policy recommendations and future research directions

Health and support services

Throughout the interview data, as has been found in studies of mothers and pregnant women who inject or are on a methadone program, current health care and social support systems represent a threat, rather than a source of support to women with hepatitis C. Klee and Jackson (1996) found that pregnant drug-using women’s fears surrounding antenatal care relating to their drug use to be justified on several counts. Women are afraid to disclose their hepatitis C and drug use because they expect negative consequences from doing so rather than receiving the support that they need.

The women in this study expressed much dissatisfaction with the hepatitis C related health care and information available. Some of this dissatisfaction was rooted in their perceived stigmatisation and resultant discrimination. Medical knowledge and understanding of hepatitis C is, however, in its infancy, and many of the studies that have been published have come to conflicting conclusions. Additionally, although making great advances, the treatments available for hepatitis C remain unacceptable, inappropriate and inaccessible to many people living with hepatitis C. The women of higher SES in this sample appeared to have far greater access to hepatitis C related health care, even if they did not always utilise it. In particular, however, they appeared to be far more likely to have been offered Interferon treatment than the women of lower SES, who were often current or past injectors. Further research is required in this area, in addition to an increased effort to provide effective and appropriate treatments for a wider range of people living with hepatitis C.
In relation to childbearing and hepatitis C, the reports of receiving inadequate and inaccurate information and advice regarding hepatitis C and childbearing are of great concern. There were several reports of being given conflicting information regarding childbearing and hepatitis C from medical professionals, which could influence their childbearing decisions in such a way as to be devastating. Becky, for example, was told that she would not be able to have children because her babies would acquire hepatitis C from her and she was likely to die at an early age anyway. Becky, and other women later managed to obtain more accurate, and less directive information and advice. It is, however, possible that there are many women with hepatitis C who have not had children that they wanted because of such misleading information. Aside from the fact that the information on which this advice was based was wholly inaccurate, it is not the role of a medical practitioner to be so directive, no matter how intentioned.

Similar problems were reported regarding information and counselling on the risk of vertical transmission of hepatitis C through breastfeeding. Although the National health and Medical Research Council guidelines state that breastfeeding should not normally be discouraged among women with hepatitis C (Commonwealth of Australia and Australian Institute for Primary Care, 2001; MacDonald et al., 2001), the interview data indicates that these guidelines are not being adhered to, even in more recent times, and this could have a negative impact upon the health and wellbeing of mothers and babies.

Giles, et al (2004) conducted a survey of Australian and New Zealand obstetrical practices regarding blood borne viruses such as hepatitis C, hepatitis B and HIV among practitioners. They found practice to be discordant with current guidelines regarding advising patients with hepatitis C (as well as hepatitis B) to have elective caesarean sections, and that there is an increased risk of vertical transmission through breastfeeding. They
attribute this poor advice to a lack of knowledge about the risks of vertical transmission of these viruses. This suggests the need for widespread improved practitioner education regarding the management of patients with hepatitis C, as well as other blood borne viruses.

In order to address the problem of receiving conflicting advice from different sources, medical professionals and support workers should only provide information and guidance as specified in authoritative guidelines. There exists a ‘National hepatitis C resource manual’ (Commonwealth of Australia and Australian Institute for Primary Care, 2001) produced for health care workers. The manual provides information on the risk of vertical transmission; testing advice; breastfeeding and caesarean section recommendations in relation to hepatitis C. The manual provides this information in a simple format. However, the recommendations made in the manual are recommendations only. Although current National Medical and Research Council guidelines recommend pre and post-test counselling, there is no legal requirement of medical professionals performing testing and providing diagnoses of hepatitis C to provide this essential counselling. Further action is required to ensure that appropriate pre and post-test counselling is performed uniformly, and that for women in particular, the issues surrounding childbearing are covered adequately and in a non-judgemental, non-directive manner.

The interview data presented in this thesis indicates that many medical professionals have a poor understanding of hepatitis C, and consequently people living with the virus have many misconceptions regarding routes of transmission, the meaning of clinical markers (Loxley et al., 2000) and what it means to live with hepatitis C, as was found in qualitative research of current injectors (Southgate and Weatherall, 2003). These misunderstandings may have serious consequences for some people living with the virus. For example, there
exists a great deal of confusion regarding what it means to have antibodies. Southgate and Weatherall (2003) found that (among other major misconceptions) some people believe that testing positive to hepatitis C antibodies means that they do not have the virus and their body has fought off the virus when previously exposed. In fact, testing positive for antibodies is actually used as an indicator that an individual has got hepatitis C. Appropriate pre and post-test counselling would help to dispel these misconceptions. It is, however, essential that guidelines are developed regarding the language in which test results and hepatitis C information are provided. The medical jargon often used by medical professionals in consultations with people who have acquired hepatitis C, along with limited medical knowledge and understanding of hepatitis C results in confusion, anxiety, poor management of the virus, and potential risks of further transmission to others.

There have been a significant number of studies both in Australia and overseas that have investigated vertical transmission of hepatitis C. However, the results and conclusions are widely variable, which is largely a result of small sample sizes and inclusion criteria (for example some include women co-infected with HIV or hepatitis B). This information requires synthesizing and being made readily available to a wide range of medical professionals in order for them to provide up to date and accurate information to their patients.

It was reported earlier in this thesis that there have been policy changes regarding the availability and purpose of the use of PCR tests (Hepatitis C Council NSW, 2004; National Hepatitis C Testing Policy Steering Committee, 2003). For some people living with hepatitis C, a PCR test may actually show that they have in fact naturally cleared the virus. For others, this test offers more information about their hepatitis C infection, and would allow them to make better informed decisions regarding childbearing, but also in other
aspects of their lives that may be affected by hepatitis C. Reducing some of the many uncertainties that surround a hepatitis C diagnosis is important in allowing those diagnosed to accept the diagnosis and manage it. While changes in testing policies are a step forward in allowing people diagnosed with hepatitis C based upon a positive hepatitis C antibody test, there remains much to be done in providing appropriate on-going management of hepatitis C. In particular, providing appropriate care for current and past injectors, and ensuring they have access to it, should be prioritised.

The statements made by the women in this study indicated that they had many misconceptions and gaps in knowledge regarding hepatitis C and childbearing, and hepatitis C in relation to motherhood. Because hepatitis C is so highly stigmatised, it may be difficult for some women to approach medical professionals for further information. That many women had received conflicting information from different sources appeared to reduce their confidence in the information they were given, and so they developed their own meanings and understandings of the risks associated with hepatitis C and childbearing and motherhood.

The nature of hepatitis C places GPs in an ideal position to provide on-going comprehensive care. However, the women in this study indicate that many GPs have a poor knowledge and understanding of hepatitis C which severely restricts what they are able to offer women living with the virus. Additionally, the stigma and discrimination associated with hepatitis C was perceived to result in inadequate care from GPs. Several women of lower SES and current injectors in particular reported their GP to be disinterested in them, which they attribute to their being injectors, or assumed to be injectors. This indicates that it is worthwhile providing further training of GPs in terms of the clinical markers and symptomology of hepatitis C, and importantly also to provide
training in the psycho-social aspects of living with hepatitis C. Whilst it will be very difficult to prevent all of the discriminatory treatment many people with hepatitis C experience in the GP setting, ensuring GPs are better informed should help to improve this situation. GPs should be encouraged to take an active role in assisting their patients with hepatitis C to manage their hepatitis C related health, particularly when Interferon treatment is not appropriate.

Some women complained that they had to see several different medical professionals for related issues. For example, some women had a methadone prescriber, a GP, a liver specialist and an obstetrician, yet none of them were in a position to be able to provide guidance about the combination of the issues surrounding hepatitis C and childbearing, which is what they really needed. The confidentiality of information was also of concern here. Whilst some women reported being frustrated at having to go through a lot of the same questions and information with each separate medical professional, others were anxious that information provided to each of these services was not shared with the others because of problems rooted in stigma and discrimination largely relating to IDU.

Women who had consulted liver specialists also expressed dissatisfaction and disappointment with their care experience and what these medical professionals were able to offer them. Again this is largely attributable to a lack of scientific knowledge and treatments for the virus in their infancy. In particular, the lack of ability to be able to provide a detailed prognosis was a particular source of anxiety for many women. Although research into treatments and the natural history of hepatitis C is on-going, these efforts must to be continued. Importantly, the findings of this research must be filtered down to practice and women should be counselled on how to live with such great uncertainty.
Some women who have been living with hepatitis C for several years had not been in contact with medical professionals regarding their hepatitis C for some time. Many of these women were not even aware that a treatment exists for hepatitis C. Thus their understanding of hepatitis C which influences their lived experience of the virus remains based upon the information they received some time ago. Significant advancements have been made in recent years; it is important to ensure these women remain in contact with services in order that they can be kept abreast of and benefit from advancements in testing, information and treatments. Stigma and discriminatory treatment acts as a deterrent to treatment seeking among women with hepatitis C, possibly to a greater extent than for men with hepatitis C. In order to ensure that women with hepatitis C do remain in contact with medical professionals regarding their hepatitis C, this discriminatory treatment must be addressed.

The Anti-Discrimination Board of New South Wales (2001) report on hepatitis C related discrimination highlighted that current anti-discrimination law does not cover all forms of hepatitis C related discrimination and as such it is very difficult to address much of it. Additionally, it was reported that very few people actually undertook any action in response to hepatitis C related discrimination. The report indicated that much change is required if hepatitis C related discrimination is to be dealt with effectively. The government appears, to be taking the opposite approach, however, and have proposed a bill that is currently being considered by the Australian parliament.

The proposed Disability Discrimination Amendment Bill 2003 would make it lawful to discriminate against persons addicted to illegal drugs who are not currently in drug treatment. The government has proposed this Bill, because they argue that it will keep work and social environments safe, respond to community concerns and force drug users into
treatment. This is clearly a step backwards, and is again based upon populist policies based on little evidence. The Bill also conflicts with the National Hepatitis C Strategy (Commonwealth Department of Health and Aged Care, 2000), which promotes ‘access and equity’ to hepatitis C related services, and promotes the ‘more effective use of existing anti-discrimination laws’ in order to reduce hepatitis C related discrimination. Several authors have written on the potential harms of the Bill if passed (Greig, 2004; Waller, 2004; Wodak, Lynch and Crofts, 2004), which include: infringement of several national commitments to human rights; damage to family wellbeing; generation of expensive litigation because of the difficulty of proving current addiction and current drug treatment; deterrence of drug users from seeking treatment; reduction of the ability of drug users to gain employment and accommodation. It represents yet another effort to reduce drug use through increasing the health social and other costs of using illicit drugs (contrary to weighty evidence). The Bill not only neglects evidence that such an approach does not work and is (The Royal Australasian College of Physicians, 2004), but overlooks the lack of drug treatment available to drug users, and the effects of discrimination on drug users and their families. As in the USA, government policies based upon a ‘Zero Tolerance’ or ‘War on Drugs’ approach create further marginalisation of severely disadvantaged groups. This punitive approach reinforces the drug user’s identity as a deviant and creates the process of secondary deviance in which drug users become engulfed in their role as a drug user and legitimate means of living become closed off to them. As Australia adopts more American-inspired illicit drug policies (Bammer, 2002), we can expect the dire consequences of those policies to resemble those found the USA.
Wider social issues

While it is possible to make improvements to the health and support services available to women with hepatitis C, addressing the wider social implications of living with the virus is more challenging as they are rooted deeply in social norms and processes. In order to minimise the negative consequences that hepatitis C has upon women’s identities we have to look to the root cause; the stigmatisation of hepatitis C which is largely attributable to its association with IDU. There is also a significant degree of misunderstanding of hepatitis C among the general public and medical professionals that contributes towards the social lived experience of hepatitis C. Education campaigns can address much of this misunderstanding. Addressing the social stigmatisation based upon social norms, and deviance from those norms is much more difficult as this requires change in public perception and social processes. Although education campaigns may assist in this process, they do not challenge the core reasons for this stigmatisation and discrimination. Women with hepatitis C, who are mostly current or past injectors pose moral as well as virological threats to other persons. In particular, the threats they pose to their children are perceived to be unacceptable, and this is expected to have social costs in terms of challenging the accepted ideals of society.

In countries such as the USA, where authorities have adopted a largely punitive approach to drug-using mothers and pregnant women, this situation is even more challenging for women with hepatitis C as the health and welfare system fuels and substantiates many of these deep-seated moral fears. In such countries, a change in government policies towards drug-using women, and thus women with hepatitis C would encourage changes in public opinion. Such changes are, however, unlikely given that government policies are often
directed by populist ideals. This is the case in Australia’s approach to ‘the Drug Problem’ in which the government has adopted punitive policies to drug users, despite vast amounts of evidence that this approach is ineffective and expensive (The Royal Australasian College of Physicians, 2004).

**Significance of the findings**

Hepatitis C is a growing problem in terms of the large and increasing number of people living with the virus in Australia, but also in terms of the social consequences associated with the stigmatised nature of the virus. It has been demonstrated throughout this thesis that even when asymptomatic, hepatitis C negatively impacts the quality of life of women living with the virus. It has also been shown that hepatitis C impacts negatively upon the social identity of women living with the virus and that the stigma they experience is often worse than that experienced by men. This is because hepatitis C conflicts with the social roles women are expected to perform, and the attributes they are required to possess. Hepatitis C serves to exacerbate the social exclusion many women injectors experience; it creates a further barrier to achieving a socially legitimate identity. Several government funded reports indicate that in order to reduce the negative consequences of living with hepatitis C a less punitive and more supportive approach is required from governments and health and social service providers. However, populist-driven government policies that contradict the findings of these reports and other research are likely to worsen the situation for not only drug dependent women, but also women with hepatitis C regardless of their injector status, because they are usually assumed to be injectors, which is usually associated with drug dependence.
Limitations of the thesis and future research directions

This thesis was a qualitative study which sought to investigate the social meanings and processes associated with hepatitis C. These detailed findings from a sample of 34 women were related to a large cross-sectional survey of women living with hepatitis C in Victoria and the ACT conducted in 2000 (Gifford et al., 2003). The sample description (chapter seven) shows that the women in this study had very similar socio-demographic characteristics to those in the WLHC sample (Gifford et al., 2003), which indicates that although the sample size is small, it is representative as far as small samples can be. While the prevalence of particular issues raised in the thesis cannot be extrapolated to the Australian population of women with hepatitis C based upon this small sample, they are of great significance and are worthy of further investigation.

To address many of the issues raised in this thesis, such as problems accessing antenatal care because of the stigmatised nature of hepatitis C, further research is required. In order to establish the prevalence of these issues, large-scale studies are required. Additionally, most of the women in this sample were drawn from the Sydney metropolitan area. Worthy of further study would be to investigate whether women from rural areas and in other states share similar or even worse experiences. It would also be worthwhile investigating whether or not any state governments are conducting more enlightened programs.

Further research is required into how best to provide the health and social support services that so many women with hepatitis C need and through stigma and discrimination are effectively denied. A consumer-based approach would be a worthy strategy, which, by giving a voice to the women for whom these services are provided, is empowering in itself. Consumer consultation should not, however, be tokenistic. Permitting women with
hepatitis C to direct the future of health and social services would not only make the services more appropriate and accessible, but would also provide these women with a greater stake in society.
References


Crockett, B. and Gifford, S. (no date) "Eyes wide shut": Narratives of women living with hepatitis C in Australia. *Women and Health*.


Hudelson, P. M. (1994) Introduction to qualitative research. In *Qualitative research for health programmes*, Division of Mental Health, Geneva.


McDonald, K. (2002) 'I was devastated to think I couldn't have a child': The role of motherhood in the lives of HIV-positive women in Australia. *Meridian*, 18, 123-141.


344


349


Western Australian Department of Justice (2002) Executive summary: Profile of women in prison. Western Australian Department of Justice: Community and Juvenile Justice Division.


Appendices

Appendix 1: Suburb of residence

<table>
<thead>
<tr>
<th>District</th>
<th>Number of women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central districts</td>
<td></td>
</tr>
<tr>
<td>Central Eastern</td>
<td>8</td>
</tr>
<tr>
<td>Inner West</td>
<td>7</td>
</tr>
<tr>
<td>Central</td>
<td>5</td>
</tr>
<tr>
<td>Eastern</td>
<td>2</td>
</tr>
<tr>
<td>Northern</td>
<td>2</td>
</tr>
<tr>
<td>Outer districts</td>
<td></td>
</tr>
<tr>
<td>Western</td>
<td>3</td>
</tr>
<tr>
<td>Southern</td>
<td>4</td>
</tr>
<tr>
<td>Other outer districts</td>
<td></td>
</tr>
<tr>
<td>Far West</td>
<td>1</td>
</tr>
<tr>
<td>Far South West</td>
<td>1</td>
</tr>
<tr>
<td>Blue Mountains</td>
<td>1</td>
</tr>
</tbody>
</table>
Appendix 2: Hepatitis C summary table

This table summarises some of the hepatitis C related health issues reported by the women.

Notes:
*Infection source*: Stated as reported by the participant reported, even if an alternative source of infection may have been probable.
*Time since diagnosis and duration of infection*: This information was not gathered in the questionnaire. In most cases, the issue arose during the interview, but given the semi-structured nature of the interview, not every participant was asked for this specific information. Estimation of duration of infection is stated as reported by participant during the interview or by the researcher during analysis (based upon other data gathered in the interview).
*Self-rated health*: Stated as reported in initial questionnaire, in participants’ own words.
*Indicates estimated by researcher

<table>
<thead>
<tr>
<th>Name</th>
<th>Infection source</th>
<th>Experienced hepatitis C discrimination</th>
<th>Nature of discrimination and who discrimination came from</th>
<th>Time since diagnosis</th>
<th>Estimated duration of infection</th>
<th>Severity of symptoms</th>
<th>Self-rated health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abby</td>
<td>IDU</td>
<td>Yes</td>
<td>Medical staff make her feel uncomfortable</td>
<td>-</td>
<td>1.5 years</td>
<td>Moderate</td>
<td>Not good</td>
</tr>
<tr>
<td>Abigail</td>
<td>Probably IDU</td>
<td>Not really</td>
<td></td>
<td>-</td>
<td>6 to 12 months</td>
<td>None</td>
<td>Good</td>
</tr>
<tr>
<td>Amy</td>
<td>IDU</td>
<td>Yes</td>
<td>Friends, neighbours and partner. Related to IDU.</td>
<td>-</td>
<td>5 years</td>
<td>Moderate</td>
<td>Kidney problems</td>
</tr>
<tr>
<td>Becky</td>
<td>IDU</td>
<td>Yes</td>
<td>Medical staff restricted access to hepatitis C and drug treatment. Judgemental attitude, especially GPs.</td>
<td>-</td>
<td>4 years</td>
<td>Moderate</td>
<td>Better than it has been</td>
</tr>
<tr>
<td>Dawn</td>
<td>Don't know</td>
<td>Yes</td>
<td>Yes, but saw it as a measure to prevent infections.</td>
<td>-</td>
<td>5-10 years*</td>
<td>None</td>
<td>Good</td>
</tr>
<tr>
<td>Ellie</td>
<td>IDU</td>
<td>Yes</td>
<td>Problems obtaining workplace health cover. Medical restricted access to some medications.</td>
<td>-</td>
<td>5-10 years*</td>
<td>Acute quite severe, current mild.</td>
<td>No clue</td>
</tr>
</tbody>
</table>
### Appendix 2: Hepatitis C summary table continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Infection source</th>
<th>Experienced hepatitis C discrimination</th>
<th>Nature of discrimination and who discrimination came from</th>
<th>Time since diagnosis</th>
<th>Estimated duration of infection</th>
<th>Severity of symptoms</th>
<th>Self-rated health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emily</td>
<td>IDU</td>
<td>Yes</td>
<td>On methadone when having baby. Medical staff treated her 'like a leper.'</td>
<td>-</td>
<td>10 years</td>
<td>None</td>
<td>Good</td>
</tr>
<tr>
<td>Fiona</td>
<td>IDU</td>
<td>Yes</td>
<td>Lack of assistance, medical staff don't want to know.</td>
<td>18 months</td>
<td>2 years</td>
<td>Moderate</td>
<td>Pretty good</td>
</tr>
<tr>
<td>Gemma</td>
<td>Don’t know</td>
<td>Yes</td>
<td>Judgemental medical staff refused to treat her because of fear on infection.</td>
<td>-</td>
<td>4 years</td>
<td>Moderate</td>
<td>Okay, but experiences nausea and fatigue</td>
</tr>
<tr>
<td>Georgia</td>
<td>Medical</td>
<td>Yes</td>
<td>From dentist regarding money because assumed to be stereotypical junkie who is dishonest.</td>
<td>-</td>
<td>14 years</td>
<td>Mild</td>
<td>Good</td>
</tr>
<tr>
<td>Hannah</td>
<td>IDU</td>
<td>Not really</td>
<td>Does not disclose in order to avoid discrimination.</td>
<td>-</td>
<td>20 years</td>
<td>Mild</td>
<td>Good</td>
</tr>
<tr>
<td>Janice</td>
<td>Don’t know</td>
<td>Not really</td>
<td>Does not disclose to avoid discrimination - especially to GP. Knows many women who have experience very bad discrimination.</td>
<td>5 years</td>
<td>5-6 years</td>
<td>Mild</td>
<td>Good</td>
</tr>
<tr>
<td>Jean</td>
<td>IDU or tattoos</td>
<td>Not really</td>
<td>Does not disclose to avoid discrimination.</td>
<td>-</td>
<td>11 years</td>
<td>Was severe, now mild</td>
<td>Okay</td>
</tr>
<tr>
<td>Jessica</td>
<td>IDU</td>
<td>Yes</td>
<td>GP assumed her to be an injector and to possess auxiliary traits.</td>
<td>3 years</td>
<td>&gt; 3 years</td>
<td>Mild</td>
<td>Fine, really well</td>
</tr>
<tr>
<td>Jocelyn</td>
<td>On purpose with infected needle</td>
<td>Yes</td>
<td>Much discrimination in all areas of life. Seen as a moral and criminal deviant.</td>
<td>10 years</td>
<td>20-30 years</td>
<td>Severe in great pain and discomfort. Feels very sick</td>
<td>Real sick</td>
</tr>
<tr>
<td>Julie</td>
<td>IDU</td>
<td>Yes</td>
<td>Avoids disclosure to prevent discrimination.</td>
<td>1 year</td>
<td>4 years</td>
<td>None</td>
<td>Good</td>
</tr>
</tbody>
</table>
## Appendix 2: Hepatitis C summary table continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Infection source</th>
<th>Experienced hepatitis C discrimination</th>
<th>Nature of discrimination and who discrimination came from</th>
<th>Time since diagnosis</th>
<th>Estimated duration of infection</th>
<th>Severity of symptoms</th>
<th>Self-rated health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Justine</td>
<td>IDU</td>
<td>Yes</td>
<td>Much discrimination, especially by medical staff and GPs. Avoids disclosure to prevent discrimination. Restricts access to services and support. Believes discrimination is why injectors don’t have hep C treatment.</td>
<td>-</td>
<td>10 years</td>
<td>Moderate/severe</td>
<td>Worrisome, could be better</td>
</tr>
<tr>
<td>Karen</td>
<td>IDU</td>
<td>Yes</td>
<td>Rejected from workplace because perceived to be ‘infectious’ and unable to function.</td>
<td>1 year</td>
<td>&gt;10 years</td>
<td>None</td>
<td>Very good</td>
</tr>
<tr>
<td>Kate</td>
<td>IDU</td>
<td>Yes</td>
<td>Obstetrician advised her to have termination because has hepatitis C. Suspected of being an injector.</td>
<td>12 years</td>
<td>17 years</td>
<td>Moderate/severe</td>
<td>Good</td>
</tr>
<tr>
<td>Kath</td>
<td>IDU</td>
<td>No</td>
<td>Discloses to avoid blame and guilt for any infections.</td>
<td>2 years</td>
<td>&gt;2 years</td>
<td>Mild</td>
<td>Very good, excellent</td>
</tr>
<tr>
<td>Kelly</td>
<td>Medical</td>
<td>Yes</td>
<td>Medical staff. Judgemental attitude and lack of assistance.</td>
<td>4 years</td>
<td>&gt;4 years</td>
<td>Moderate</td>
<td>Pretty good</td>
</tr>
<tr>
<td>Kylie</td>
<td>IDU</td>
<td>Not really</td>
<td>Feels like she’s not like everyone else when receiving medical care.</td>
<td>2 years</td>
<td>&gt;2 years</td>
<td>None</td>
<td>Quite good</td>
</tr>
<tr>
<td>Linda</td>
<td>IDU</td>
<td>Yes</td>
<td>Obstetrician refused to treat her when pregnant because feared infection.</td>
<td>5 years</td>
<td>&gt;5 years</td>
<td>Moderate/severe</td>
<td>Average</td>
</tr>
<tr>
<td>Lindsay</td>
<td>Piercing</td>
<td>Yes</td>
<td>Work, family and medical staff. Judged for being a drug user.</td>
<td>2 years</td>
<td>2 years</td>
<td>Mild/moderate</td>
<td>Moderate</td>
</tr>
<tr>
<td>Naomi</td>
<td>IDU</td>
<td>Not really</td>
<td>Has heard lots of stories of discrimination but not experienced any herself.</td>
<td>3 years</td>
<td>&gt;3 years</td>
<td>Mild</td>
<td>Terrible</td>
</tr>
<tr>
<td>Rebecca</td>
<td>IDU</td>
<td>Not really</td>
<td>Go to IDU specialising doctors to avoid discrimination.</td>
<td>15 years</td>
<td></td>
<td>Moderate</td>
<td>On and off</td>
</tr>
</tbody>
</table>
### Appendix 2: Hepatitis C summary table continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Infection source</th>
<th>Experienced hepatitis C discrimination</th>
<th>Nature of discrimination and who discrimination came from</th>
<th>Time since diagnosis</th>
<th>Estimated duration of infection</th>
<th>Severity of symptoms</th>
<th>Self-rated health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sally</td>
<td>IDU</td>
<td>Yes</td>
<td>Medical staff have been judgemental attitude about drug use and assumed stereotypical characteristics.</td>
<td>15 years</td>
<td>&gt; 15 years</td>
<td>Mild</td>
<td>Reasonably good</td>
</tr>
<tr>
<td>Sarah</td>
<td>IDU</td>
<td>Not really</td>
<td>Most people have been fine. Always discloses to avoid any infections and guilt.</td>
<td>10 years</td>
<td>20 years</td>
<td>Mild</td>
<td>Very well</td>
</tr>
<tr>
<td>Sharon</td>
<td>IDU</td>
<td>Not really</td>
<td>Attends Kings Cross health services for street people. Discloses freely to understanding people.</td>
<td>12 years</td>
<td>&gt;12 years</td>
<td>Moderate/severe</td>
<td>No response recorded</td>
</tr>
<tr>
<td>Sophie</td>
<td>Medical</td>
<td>Not really</td>
<td>No discrimination but does disclose hepatitis C status. Does not have much to do with doctors as dislikes medical model of care.</td>
<td>-</td>
<td>About 5 years*</td>
<td>None</td>
<td>Fabulous</td>
</tr>
<tr>
<td>Tammy</td>
<td>IDU</td>
<td>Yes</td>
<td>Medical staff. Prevents much by not disclosing.</td>
<td>-</td>
<td>15 years</td>
<td>Quite severe</td>
<td>Good</td>
</tr>
<tr>
<td>Theresa</td>
<td>IDU</td>
<td>Yes</td>
<td>Medical staff made her feel uncomfortable.</td>
<td>-</td>
<td>20 years</td>
<td>Severe in past but mild/moderate now</td>
<td>Good</td>
</tr>
<tr>
<td>Valerie</td>
<td>Piercing</td>
<td>Yes</td>
<td>Treated as though she ‘had bubonic plague’ by some doctors others discriminate based on IDU</td>
<td>-</td>
<td>12-15 years</td>
<td>Moderate</td>
<td>Quite good</td>
</tr>
<tr>
<td>Veronica</td>
<td>IDU</td>
<td>Don’t know</td>
<td>Depends on how you perceive the situation as to whether or not you are discriminated against.</td>
<td>-</td>
<td>17 years</td>
<td>Mild</td>
<td>Very good</td>
</tr>
</tbody>
</table>
Appendix 3: Injecting drug use and methadone programme enrolment summary table

Not all participants were specifically asked about methadone maintenance in the questionnaire or open-ended interview. This issue was usually discussed in the interviews. However, there may have been more women who were on a methadone maintenance programme at the time of interview or had been in the past than are stated here.

Current injecting was defined as having injected in the last 12 months.

<table>
<thead>
<tr>
<th>Name</th>
<th>Ever IDU</th>
<th>Current IDU*</th>
<th>Time since last injection</th>
<th>Methadone maintenance program</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abby</td>
<td>Yes</td>
<td>Yes</td>
<td>3 months</td>
<td>Current</td>
</tr>
<tr>
<td>Abigail</td>
<td>Yes</td>
<td>Yes</td>
<td>Several months</td>
<td>Current</td>
</tr>
<tr>
<td>Amy</td>
<td>Yes</td>
<td>Yes</td>
<td>3 days</td>
<td>Unclear</td>
</tr>
<tr>
<td>Becky</td>
<td>Yes</td>
<td>Yes</td>
<td>1 month</td>
<td>Current</td>
</tr>
<tr>
<td>Dawn</td>
<td>Yes</td>
<td>No</td>
<td>19 months</td>
<td>Current</td>
</tr>
<tr>
<td>Ellie</td>
<td>Yes</td>
<td>Yes</td>
<td>1 day</td>
<td>Current</td>
</tr>
<tr>
<td>Emily</td>
<td>Yes</td>
<td>Yes</td>
<td>&lt; 1 day</td>
<td>Current</td>
</tr>
<tr>
<td>Fiona</td>
<td>Yes</td>
<td>Yes</td>
<td>1 day</td>
<td>No</td>
</tr>
<tr>
<td>Gemma</td>
<td>Yes</td>
<td>Yes</td>
<td>1 month</td>
<td>Current</td>
</tr>
<tr>
<td>Georgina</td>
<td>Yes</td>
<td>Yes</td>
<td>1 day</td>
<td>Current</td>
</tr>
<tr>
<td>Hannah</td>
<td>Yes</td>
<td>No</td>
<td>25 years</td>
<td>No</td>
</tr>
<tr>
<td>Janice</td>
<td>Yes</td>
<td>Yes</td>
<td>&gt; 1 week</td>
<td>Current</td>
</tr>
<tr>
<td>Jean</td>
<td>Yes</td>
<td>Yes</td>
<td>1 week</td>
<td>Unclear</td>
</tr>
<tr>
<td>Jessica</td>
<td>No</td>
<td>No</td>
<td>NA</td>
<td>No</td>
</tr>
<tr>
<td>Jocelyn</td>
<td>Yes</td>
<td>No</td>
<td>23 years</td>
<td>No</td>
</tr>
<tr>
<td>Julie</td>
<td>Yes</td>
<td>Yes</td>
<td>1 week</td>
<td>Current</td>
</tr>
<tr>
<td>Justine</td>
<td>Yes</td>
<td>Yes</td>
<td>1 day</td>
<td>Current</td>
</tr>
<tr>
<td>Karen</td>
<td>No</td>
<td>No</td>
<td>NA</td>
<td>No</td>
</tr>
<tr>
<td>Kate</td>
<td>No</td>
<td>No</td>
<td>NA</td>
<td>No</td>
</tr>
<tr>
<td>Kath</td>
<td>Yes</td>
<td>Yes</td>
<td>4 months</td>
<td>Current</td>
</tr>
<tr>
<td>Kelly</td>
<td>Yes</td>
<td>No</td>
<td>3 years</td>
<td>No</td>
</tr>
<tr>
<td>Kylie</td>
<td>Yes</td>
<td>Yes</td>
<td>1 day</td>
<td>Current</td>
</tr>
<tr>
<td>Linda</td>
<td>Yes</td>
<td>Yes</td>
<td>3 weeks</td>
<td>Current</td>
</tr>
<tr>
<td>Lindsay</td>
<td>Yes</td>
<td>Yes</td>
<td>4 months</td>
<td>Unclear</td>
</tr>
<tr>
<td>Naomi</td>
<td>Yes</td>
<td>Yes</td>
<td>Unclear</td>
<td>Current</td>
</tr>
<tr>
<td>Rebecca</td>
<td>Yes</td>
<td>Yes</td>
<td>&lt; 1 day</td>
<td>Past</td>
</tr>
<tr>
<td>Sally</td>
<td>Yes</td>
<td>Yes</td>
<td>1 day</td>
<td>Current</td>
</tr>
<tr>
<td>Sarah</td>
<td>Yes</td>
<td>No</td>
<td>25 years</td>
<td>No</td>
</tr>
<tr>
<td>Sharon</td>
<td>Yes</td>
<td>Yes</td>
<td>&lt; 1 day</td>
<td>Past</td>
</tr>
<tr>
<td>Sophie</td>
<td>Yes</td>
<td>No</td>
<td>7 years ago</td>
<td>Unclear</td>
</tr>
<tr>
<td>Tammy</td>
<td>Yes</td>
<td>Yes</td>
<td>1 day</td>
<td>Current</td>
</tr>
<tr>
<td>Theresa</td>
<td>Yes</td>
<td>Yes</td>
<td>15 years ago</td>
<td>No</td>
</tr>
<tr>
<td>Valerie</td>
<td>Yes</td>
<td>No</td>
<td>1 year</td>
<td>Current</td>
</tr>
<tr>
<td>Veronica</td>
<td>Yes</td>
<td>Yes</td>
<td>&lt; 1 day</td>
<td>Current</td>
</tr>
</tbody>
</table>
Appendix 4: Social supports

This table summarises the social relationships that were reported by participants and the social support available to them through these relationships.

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship with family</th>
<th>Partner</th>
<th>Living with partner</th>
<th>Abusive partner</th>
<th>IDU partner</th>
<th>Other sources of support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abby</td>
<td>Poor relationship with family because of her drug use and association with men they do not approve of.</td>
<td>Yes</td>
<td>Yes</td>
<td>No but he was highly dependent on her and exercised a great deal of control over her.</td>
<td>Yes although he was trying to stop injecting alongside Abby because she was pregnant.</td>
<td>Partner's mother</td>
</tr>
<tr>
<td>Abigail</td>
<td>Good relationship with mother who she lives with</td>
<td>No but was in contact with father of her new born baby</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>No</td>
</tr>
<tr>
<td>Amy</td>
<td>Lost her mother and father as a young child and brought up in state care.</td>
<td>Has split with her husband who has custody of six of her seven children. Her relationship to him is now very poor.</td>
<td>NA</td>
<td>Although no longer with him, her partner was physically abusive throughout their long term relationship</td>
<td>NA</td>
<td>No</td>
</tr>
<tr>
<td>Becky</td>
<td>No family in Australia and very little contact with family in the UK.</td>
<td>Divorced several months prior to interview. Had recently began new relationship.</td>
<td>Yes</td>
<td>Current partner supportive. Ex-husband physically abusive.</td>
<td>Not clear, however, he did appear to be very stable (he was present at time of interview).</td>
<td>Amy’s oldest child lives with her and provides some support. Street-based friends and associates at Kings Cross.</td>
</tr>
<tr>
<td>Dawn</td>
<td>Good relationship with her own family and her husband’s family. They provided a good source of support although they live outside NSW.</td>
<td>Yes, very good relationship with husband.</td>
<td>Yes</td>
<td>No, husband very supportive.</td>
<td>Her husband was doing very well on a methadone program, alongside Dawn.</td>
<td>No</td>
</tr>
<tr>
<td>Ellie</td>
<td>Very good relationship with mother who she was living with.</td>
<td>No, recently split from partner.</td>
<td>Although split up, her partner was living with Ellie and her mother</td>
<td>No</td>
<td>Recent ex-partner was an injector but appeared stable at time of interview.</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix 4: Social supports continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship with family</th>
<th>Partner</th>
<th>Living with partner</th>
<th>Abusive partner</th>
<th>IDU partner</th>
<th>Other sources of support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emily</td>
<td>Unclear.</td>
<td>Yes, reasonably good relationship.</td>
<td>Yes</td>
<td>No</td>
<td>He was an ex-injector who appeared relatively stable at time of interview.</td>
<td>Friend and sister-in-law.</td>
</tr>
<tr>
<td>Fiona</td>
<td>Reasonable relationship with parents but a strained relationship with her sister as a result of her having hepatitis C and her IDU.</td>
<td>No</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>No</td>
</tr>
<tr>
<td>Gemma</td>
<td>Quite a good relationship with mother.</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Partner was highly drug dependent and living a very chaotic life as a result. He was in need of a great deal of support although he appeared to offer an important source of support to Gemma.</td>
<td>No</td>
</tr>
<tr>
<td>Georgia</td>
<td>Reasonable relationship with family. History of substance dependence in family.</td>
<td>Yes, a good source of support.</td>
<td>Yes</td>
<td>No</td>
<td>Was recreational IDU at time of interview but working in very responsible demanding job.</td>
<td>No, recently moved to Sydney from WA and knows very few people outside of work. Unable to disclose IDU to most people as she would lose her job.</td>
</tr>
<tr>
<td>Hannah</td>
<td>Good relationship with family.</td>
<td>Yes, very good relationship.</td>
<td>Yes</td>
<td>No, husband very supportive.</td>
<td>No. Like Hannah he sometimes used (non-IDU) recreational drugs but was very stable and maintains a responsible well-paid job.</td>
<td>Friends.</td>
</tr>
<tr>
<td>Janice</td>
<td>Unclear from interview</td>
<td>No, has split from husband.</td>
<td>Yes, although split form husband was living with Janice and her children.</td>
<td>No</td>
<td>Ex-husband also injects but is very stable.</td>
<td></td>
</tr>
</tbody>
</table>


### Appendix 4: Social supports continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship with family</th>
<th>Partner</th>
<th>Living with partner</th>
<th>Abusive partner</th>
<th>IDU partner</th>
<th>Other sources of support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jean</td>
<td>Does not have family in Australia, Visits family in New Zealand occasionally and appeared to have reasonable relationship with them.</td>
<td>No</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Friends.</td>
</tr>
<tr>
<td>Jessica</td>
<td>No family in Australia. Appeared to have reasonable relationship with family in the UK.</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>NA</td>
<td>No, Jessica felt very lonely and had struggled to make friends since moving to Australia form the UK a couple of years previous.</td>
</tr>
<tr>
<td>Jocelyn</td>
<td>No family in Australia. Does not appear to have had any contact with family in the Netherlands for some time.</td>
<td>No, husband died over 25 years ago from drug overdose.</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Has two children who are now around age 20. They provide some limited support. Some friends also provide practical assistance when she is very sick.</td>
</tr>
<tr>
<td>Julie</td>
<td>Good relationship with family.</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>NA</td>
<td>Friends she studies with. However, she could not disclose her IDU or hepatitis C to them.</td>
</tr>
<tr>
<td>Justine</td>
<td>Reasonably good relationship with mother and sister in Melbourne.</td>
<td>No</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Very limited support from friends.</td>
</tr>
<tr>
<td>Karen</td>
<td>Unclear</td>
<td>Yes, good relationship with husband.</td>
<td>Yes</td>
<td>No</td>
<td>NA</td>
<td>No</td>
</tr>
<tr>
<td>Kate</td>
<td>Good relationship with her own family and her partner’s family.</td>
<td>Yes, very strong supportive relationship.</td>
<td>Yes</td>
<td>No</td>
<td>NA</td>
<td>Friends but felt she could not disclose her hepatitis C to most of them.</td>
</tr>
</tbody>
</table>
### Appendix 4: Social supports continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship with family</th>
<th>Partner</th>
<th>Living with partner</th>
<th>Abusive partner</th>
<th>IDU partner</th>
<th>Other sources of support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kath</td>
<td>Quite a good relationship with mother and siblings.</td>
<td>Yes, reasonably good relationship.</td>
<td>No</td>
<td>No</td>
<td>Yes, he had problematic drug dependency. Still able to provide an important source of support though.</td>
<td>No</td>
</tr>
<tr>
<td>Kelly</td>
<td>Very good relationship with mother and sister but mother recently moved back to the UK.</td>
<td>No</td>
<td>NA</td>
<td>NA</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>Kylie</td>
<td>No family in Australia. No contact with family in New Zealand for several years and did not know of their whereabouts.</td>
<td>Yes</td>
<td>Sometimes, he also has his own place where he stays in order to minimise conflict and physical abuse of Kylie.</td>
<td>Yes, he had physically abused her for several years, which is the main reason they lost custody of their first child.</td>
<td>He did not inject but he did have a problematic alcohol problem.</td>
<td>A friend.</td>
</tr>
<tr>
<td>Linda</td>
<td>Very good relationship with mother who she was living very close to.</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>He had severe drug dependency problems and required a lot of support from her.</td>
<td>No</td>
</tr>
<tr>
<td>Lindsay</td>
<td>Has very poor relationship with her parents because of her drug use.</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Her partner was an IDU and is quite sick from hepatitis C.</td>
<td>No</td>
</tr>
<tr>
<td>Naomi</td>
<td>No family in Australia. Partner's parents deceased.</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Rebecca</td>
<td>Good relationship with her family but not much contact with them recently.</td>
<td>Divorced from husband several years previous. Identifies as gay now but did not report a current partner.</td>
<td>No</td>
<td>Ex-husband was abusive.</td>
<td>NA</td>
<td>Other sex workers and street based IDU in Kings Cross.</td>
</tr>
<tr>
<td>Sally</td>
<td>Reasonably good relationship with family in Victoria.</td>
<td>No</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>A strong network of friends who also inject.</td>
</tr>
</tbody>
</table>
## Appendix 4: Social supports continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship with family</th>
<th>Partner</th>
<th>Living with partner</th>
<th>Abusive partner</th>
<th>IDU partner</th>
<th>Other sources of support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah</td>
<td>Parents dead but had very good relationship with them before they died.</td>
<td>Yes, very good relationship.</td>
<td>Yes</td>
<td>No, husband very supportive.</td>
<td>No, he has never injected drugs.</td>
<td>Friends.</td>
</tr>
<tr>
<td>Sharon</td>
<td>Good relationship with father who was caring for her child.</td>
<td>No</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Other IDU and sex workers around Kings Cross.</td>
</tr>
<tr>
<td>Sophie</td>
<td>Good relationship with her mother who she was living with.</td>
<td>No</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Quite strong network of friends.</td>
</tr>
<tr>
<td>Tammy</td>
<td>Unclear from interview.</td>
<td>No</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>Good friendship network very supportive.</td>
</tr>
<tr>
<td>Theresa</td>
<td>Parents dead but has many siblings who she has a pretty good relationship with.</td>
<td>Yes, a good strong relationship.</td>
<td>Yes</td>
<td>No</td>
<td>No he has never injected drugs.</td>
<td>Friends</td>
</tr>
<tr>
<td>Valerie</td>
<td>Good relationship with mother who she was living with.</td>
<td>No</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>No.</td>
</tr>
<tr>
<td>Veronica</td>
<td>Pretty good relationship with mother who was living in Victoria.</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes, partner physically abusive.</td>
<td>Partner emotionally unstable. Although he appeared to use drugs, the extent to which was not made clear.</td>
<td>No.</td>
</tr>
</tbody>
</table>
### Appendix 5: Hepatitis C and childbearing

This table summarises some of the key issues involved in the ways that hepatitis C affects childbearing decisions and experiences of motherhood.

Note: Not all women were asked if they had ever terminated a pregnancy. Those stated as never having had a termination may have actually have done so but this was not discussed during the interview.

<table>
<thead>
<tr>
<th>Name</th>
<th>Biggest hepatitis C concerns</th>
<th>Existing children</th>
<th>Desire for (more) children in future</th>
<th>Currently pregnant</th>
<th>Termination history</th>
<th>Diagnosed with hepatitis C before pregnancy</th>
<th>Diagnosed with hepatitis C during pregnancy</th>
<th>Hepatitis C in relation to childbearing</th>
<th>Children in custody of others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abby</td>
<td>Infecting someone else, especially her child.</td>
<td>1</td>
<td>Yes</td>
<td>Yes</td>
<td>1</td>
<td>No</td>
<td>No</td>
<td>Hepatitis C a concern</td>
<td>1</td>
</tr>
<tr>
<td>Abigail</td>
<td>Vertical transmission (to child she had recently had).</td>
<td>1</td>
<td>Maybe</td>
<td>No</td>
<td>0</td>
<td>No</td>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Amy</td>
<td>Infect her children or her friends she injects with.</td>
<td>7</td>
<td>No</td>
<td>No</td>
<td>0</td>
<td>No</td>
<td>No</td>
<td>Hepatitis C not a major concern.</td>
<td>6</td>
</tr>
<tr>
<td>Becky</td>
<td>Future ill health</td>
<td>0</td>
<td>Yes</td>
<td>No</td>
<td>0</td>
<td>NA</td>
<td>NA</td>
<td>Hepatitis C central to childbearing largely because of treatment.</td>
<td></td>
</tr>
<tr>
<td>Dawn</td>
<td>When first diagnosed very concerned about vertical transmission. Now feels okay about that.</td>
<td>1</td>
<td>Yes</td>
<td>Yes</td>
<td>0</td>
<td>Yes</td>
<td>No</td>
<td>Hepatitis C not a major concern.</td>
<td></td>
</tr>
<tr>
<td>Ellie</td>
<td>Future ill health and death.</td>
<td>0</td>
<td>Yes</td>
<td>No</td>
<td>0</td>
<td>NA</td>
<td>NA</td>
<td>Hepatitis C a factor in childbearing in relation to her own health and transmission.</td>
<td></td>
</tr>
<tr>
<td>Emily</td>
<td>Serious liver damage.</td>
<td>1</td>
<td>No</td>
<td>No</td>
<td>0</td>
<td>No</td>
<td>Yes</td>
<td>Hepatitis C not a major factor.</td>
<td>No</td>
</tr>
<tr>
<td>Fiona</td>
<td>Effects of disclosure.</td>
<td>0</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>Yes</td>
<td>No</td>
<td>Hepatitis C central to childbearing because of emotional and physical health.</td>
<td></td>
</tr>
</tbody>
</table>

366
### Appendix 5: Hepatitis C and childbearing continued ...

<table>
<thead>
<tr>
<th>Name</th>
<th>Biggest hepatitis C concerns</th>
<th>Existing children</th>
<th>Desire for (more) children in future</th>
<th>Currently pregnant</th>
<th>Termination history</th>
<th>Diagnosed with hepatitis C before pregnancy</th>
<th>Diagnosed with hepatitis C during pregnancy</th>
<th>Hepatitis C in relation to childbearing</th>
<th>Children in custody of others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gemma</td>
<td>Vertical transmission (to child she has already had).</td>
<td>1</td>
<td>Yes</td>
<td>No</td>
<td>0</td>
<td>Yes</td>
<td>No</td>
<td>Hepatitis C a factor in childbearing largely because of medical discrimination based on hepatitis C, IDU and SES.</td>
<td>1</td>
</tr>
<tr>
<td>Georgia</td>
<td>Vertical transmission to child she wants to have soon.</td>
<td>0</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>NA</td>
<td>NA</td>
<td>Hepatitis C is a factor, particularly for her partner in relation to their own health and vertical transmission.</td>
<td>NA</td>
</tr>
<tr>
<td>Hannah</td>
<td>Serious liver damage and death</td>
<td>0</td>
<td>Yes</td>
<td>Probably (yet to be confirmed)</td>
<td>0</td>
<td>Yes</td>
<td>No</td>
<td>Hepatitis C a major factor in childbearing in relation to her own future health.</td>
<td>NA</td>
</tr>
<tr>
<td>Janice</td>
<td>Vertical transmission to existing children.</td>
<td>2</td>
<td>No</td>
<td>No</td>
<td>0</td>
<td>No</td>
<td>No</td>
<td>Hepatitis C not a factor.</td>
<td>No</td>
</tr>
<tr>
<td>Jean</td>
<td>Serious liver damage</td>
<td>1</td>
<td>Maybe</td>
<td>No</td>
<td>0</td>
<td>Yes</td>
<td></td>
<td>Hepatitis C a significant but not major factor in relation to her own health.</td>
<td>No</td>
</tr>
<tr>
<td>Jessica</td>
<td>Death</td>
<td>1</td>
<td>Yes</td>
<td>No</td>
<td>0</td>
<td>No</td>
<td>No</td>
<td>Hepatitis C a major factor in childbearing in relation to her own health.</td>
<td>No</td>
</tr>
<tr>
<td>Jocelyn</td>
<td>Poverty from being unable to work and paying for medicines and associated costs.</td>
<td>2</td>
<td>No</td>
<td>No</td>
<td>0</td>
<td>No</td>
<td></td>
<td>Hepatitis C not a factor because now 'too old', but in terms of effects on her health it would be a factor.</td>
<td>No</td>
</tr>
<tr>
<td>Julie</td>
<td>Issues around having children: transmission and getting too sick to care for them.</td>
<td>0</td>
<td>Yes</td>
<td>No</td>
<td>1</td>
<td>NA</td>
<td>NA</td>
<td>Hepatitis C a factor in terms of her own health.</td>
<td>NA</td>
</tr>
<tr>
<td>Justine</td>
<td>Future ill health and death</td>
<td>0</td>
<td>Maybe</td>
<td>No</td>
<td>0</td>
<td>NA</td>
<td>NA</td>
<td>Hepatitis C a factor in terms of her own health. Also medical discrimination and lack of support for women with hepatitis C.</td>
<td>NA</td>
</tr>
</tbody>
</table>
## Appendix 5: Hepatitis C and childbearing continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Biggest hepatitis C concerns</th>
<th>Existing children</th>
<th>Desire for (more) children in future</th>
<th>Currently pregnant</th>
<th>Termination history</th>
<th>Diagnosed with hepatitis C before pregnancy</th>
<th>Diagnosed with hepatitis C during pregnancy</th>
<th>Hepatitis C in relation to childbearing</th>
<th>Children in custody of others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Karen</td>
<td>Doctors interfering with life and giving poor, judgemental advice.</td>
<td>3</td>
<td>No</td>
<td>No</td>
<td>0</td>
<td>No</td>
<td>No</td>
<td>Hepatitis C not a factor.</td>
<td>No</td>
</tr>
<tr>
<td>Kate</td>
<td>Stigma</td>
<td>2</td>
<td>Yes</td>
<td>No</td>
<td>0</td>
<td>Yes</td>
<td>No</td>
<td>Hepatitis C not a factor.</td>
<td>No</td>
</tr>
<tr>
<td>Kath</td>
<td>Vertical transmission</td>
<td>2</td>
<td>Unclear</td>
<td>Yes</td>
<td>3</td>
<td>Before current pregnancy but not previous two.</td>
<td>No</td>
<td>Hepatitis C not a factor.</td>
<td>No</td>
</tr>
<tr>
<td>Kelly</td>
<td>Vertical transmission</td>
<td>2</td>
<td>Yes</td>
<td>No</td>
<td>0</td>
<td>No</td>
<td>Yes</td>
<td>Hepatitis C a consideration but not a major factor.</td>
<td>No</td>
</tr>
<tr>
<td>Kylie</td>
<td>Future ill health</td>
<td>1</td>
<td>Maybe</td>
<td>Yes</td>
<td>4</td>
<td>Yes</td>
<td>No</td>
<td>Hepatitis C a factor in terms of her own health but not a major factor.</td>
<td>1</td>
</tr>
<tr>
<td>Linda</td>
<td>Issues around having children: transmission and getting too sick to care for them.</td>
<td>1</td>
<td>Yes</td>
<td>No</td>
<td>0</td>
<td>No</td>
<td>No</td>
<td>Hepatitis C a consideration but not a major factor.</td>
<td>No</td>
</tr>
<tr>
<td>Lindsay</td>
<td>Social exclusion because of lack of understanding among general population.</td>
<td>0</td>
<td>Yes</td>
<td>No</td>
<td>0</td>
<td>NA</td>
<td>NA</td>
<td>Hepatitis C a factor in terms of treatment for at least one of them as well as health of one of them.</td>
<td>No</td>
</tr>
<tr>
<td>Naomi</td>
<td>Liver cancer</td>
<td>1</td>
<td>Maybe</td>
<td>No</td>
<td>2</td>
<td>No</td>
<td>No</td>
<td>Hepatitis C not a factor - may be a consideration.</td>
<td>1</td>
</tr>
<tr>
<td>Rebecca</td>
<td>Diet because she lives on the street.</td>
<td>1</td>
<td>No</td>
<td>No</td>
<td>0</td>
<td>No</td>
<td>No</td>
<td>Hepatitis C a factor.</td>
<td>No</td>
</tr>
<tr>
<td>Sally</td>
<td>Lack of information about hep C in relation to childbearing and motherhood.</td>
<td>0</td>
<td>No</td>
<td>No</td>
<td>0</td>
<td>NA</td>
<td>NA</td>
<td>Hepatitis C a factor in terms of vertical transmission, her own health and medical discrimination.</td>
<td>NA</td>
</tr>
</tbody>
</table>
### Appendix 5: Hepatitis C and childbearing continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Biggest hepatitis C concerns</th>
<th>Existing children</th>
<th>Desire for (more) children in future</th>
<th>Currently pregnant</th>
<th>Termination history</th>
<th>Diagnosed with hepatitis C before pregnancy</th>
<th>Diagnosed with hepatitis C during pregnancy</th>
<th>Hepatitis C in relation to childbearing</th>
<th>Children in custody of others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah</td>
<td>Liver damage and associated sickness.</td>
<td>1</td>
<td>No</td>
<td>No</td>
<td>1 (1 of twins who had a disorder)</td>
<td>Yes</td>
<td>No</td>
<td>Hepatitis C a factor in terms of her own health. Vertical transmission was a big consideration when having her first child recently.</td>
<td>No</td>
</tr>
<tr>
<td>Sharon</td>
<td>Lack of understanding among others about transmission risks.</td>
<td>1</td>
<td>Unclear</td>
<td>No</td>
<td>0</td>
<td>No</td>
<td>No</td>
<td>Hepatitis C a factor determining childbearing mainly in terms of the risks of vertical transmission based upon her own health.</td>
<td>1</td>
</tr>
<tr>
<td>Sophie</td>
<td>Money because being sick is expensive.</td>
<td>0</td>
<td>No</td>
<td>No</td>
<td>0</td>
<td>NA</td>
<td>NA</td>
<td>Hepatitis C a consideration but not a major factor.</td>
<td>NA</td>
</tr>
<tr>
<td>Tammy</td>
<td>Serious liver damage.</td>
<td>0</td>
<td>No</td>
<td>No</td>
<td>0</td>
<td>NA</td>
<td>NA</td>
<td>Hepatitis C is a factor.</td>
<td>NA</td>
</tr>
<tr>
<td>Theresa</td>
<td>Future ill health and death.</td>
<td>1</td>
<td>No</td>
<td>No</td>
<td>0</td>
<td>NA</td>
<td>NA</td>
<td>Hepatitis C central to childbearing mainly in terms of her own health.</td>
<td>Teenage birth: child was taken from her and adopted out</td>
</tr>
<tr>
<td>Valerie</td>
<td>Many other current problems, so hepatitis C not a priority</td>
<td>0</td>
<td>No</td>
<td>No</td>
<td>0</td>
<td>NA</td>
<td>NA</td>
<td>Hepatitis C a major factor influencing childbearing in terms of the overall effects it has had on her life.</td>
<td>NA</td>
</tr>
<tr>
<td>Veronica</td>
<td>Being able to care for her existing children and future child.</td>
<td>2</td>
<td>Maybe</td>
<td>Yes</td>
<td>0</td>
<td>Yes for all pregnancies</td>
<td>No</td>
<td>Hepatitis C not a major factor – but is a consideration.</td>
<td>No</td>
</tr>
</tbody>
</table>
### Appendix 6: Summary of childbearing decisions and dilemmas relating to hepatitis C

<table>
<thead>
<tr>
<th>Name</th>
<th>Reason and factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abby</td>
<td>Partner very much wanted a child with her. She agreed to continue with the pregnancy on the condition that they both give up their ‘junkie lifestyle’ and crime. She wanted to regain custody of her existing child who was in the custody of the father. The father of her first child used her hepatitis C status against her to help him gain custody. Hepatitis C does not appear to be a big factor but is a source of concern.</td>
</tr>
<tr>
<td>Abigail</td>
<td>Discovered she was hepatitis C positive while pregnant. This was a major shock at first but was reassured that she and her baby would be fine by medical staff. Her only fear was of vertical transmission. Partner tried to reduce drug use when Abigail got pregnant, but his drug use remained problematic. She was unsure about whether she wanted more children.</td>
</tr>
<tr>
<td>Amy</td>
<td>Already had seven children and they are not in her custody. Amy reported that she does not want any more.</td>
</tr>
<tr>
<td>Annie</td>
<td>Does not want children because she feels she is too old and does not feel ‘maternal’. Hepatitis C was factored into this decision.</td>
</tr>
<tr>
<td>Becky</td>
<td>Always wanted children. Ex-husband was very focussed on them having children. When she was diagnosed with hepatitis C, they thought she would be unable to have children. This contributed to her divorce. Becky wanted to know that she could have children and that she is ‘normal’. Not having a husband now and having hepatitis C, as well as being on MMT and doing sex work are worrying in relation to having a child. Despite these perceived barriers, she remained determined to have a baby.</td>
</tr>
<tr>
<td>Dawn</td>
<td>Family building was the ‘next step’ in Dawn’s marriage. She wanted to have four children in total, before herself and partner are too old. Money had nothing to do with it. They had accepted that they will never have much financially. Hepatitis C was not a major issue as they considered the risks of vertical transmission and childhood hepatitis C to be minimal. MMT a much greater concern in regards to childbearing.</td>
</tr>
<tr>
<td>Ellie</td>
<td>Wants children when she ‘meets the right guy’. It has been ‘instilled’ in her to want children. It’s what we’re ‘here to do.’ Wants to create a ‘better’ family than she had as a child. Partner money and health (some HCV related) most important factors.</td>
</tr>
</tbody>
</table>
Appendix 6: Summary of childbearing decisions and dilemmas and how they relate to hepatitis C continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Reasons and factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emily</td>
<td>Decided she will not have any more children because of her older age and poor health. She considers her partner to also be ‘too old’ and that there would be too large a gap between her existing son and a new baby. Emily had experienced fertility problems and was not using any contraception as a result. Emily expressed regret that she had not had a large family, but believes this opportunity to have passed.</td>
</tr>
<tr>
<td>Fiona</td>
<td>Recently terminated a pregnancy, largely because of hepatitis C and related factors. Decided not to continue the pregnancy because she was too emotionally and financially unstable, which she attributes much of to her hepatitis C. Would like to have children one day, but would like it to be planned and for her emotional health to be better.</td>
</tr>
<tr>
<td>Gemma</td>
<td>Decided not to have any more children for the time being at least because of medical discrimination, based on her IDU and hepatitis C. Gemma has experienced much discrimination, including when she had her child. She reported she may reconsider having another child in the future but her life was currently too unstable. Gemma was also fearful of experiencing post-natal depression again, as she did with her first baby. Her existing daughter was in state care and her partner had severe drug dependence problems and was very chaotic.</td>
</tr>
<tr>
<td>Georgia</td>
<td>Georgia felt she needed to have a child soon, as she was getting too old. She had a partner who she expects to stay with in the long term, who also has hepatitis C. However, they have not been together very long. Georgia recently terminated a pregnancy because she had only just met her partner and their financial situation was too unstable. She reported wanting to experience motherhood very much and thought she would be a good mother. Hepatitis C was not a major factor for her but it is to her partner, because of the risk of vertical transmission and their future health.</td>
</tr>
<tr>
<td>Hannah</td>
<td>Hannah thought she was pregnant at the time of the interview and was happy about this. She wanted to have children soon, before she becomes too old. She was not sure if she will be a good mother. Hannah will decide whether to have further children in the future depending on her health (directly hepatitis C related) and how she copes with her first child.</td>
</tr>
<tr>
<td>Janice</td>
<td>Janice had already completed her desired family size. She does not want more children based on a ‘lifestyle choice.’ This decision had nothing to do with her having hepatitis C.</td>
</tr>
<tr>
<td>Jean</td>
<td>It would be too difficult for Jean to have another child now, because of her age and health. Hepatitis C was a factor in arriving at this conclusion because of its potential effects upon her health and the risk of vertical transmission. However, having another child was something she been considering recently. Fertility problems in the past have made her want a child.</td>
</tr>
</tbody>
</table>
Appendix 6: Summary of childbearing decisions and dilemmas and how they relate to hepatitis C continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Reasons and factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jessica</td>
<td>Jessica wanted to have more children in the next couple of years. Before going ahead with this however, she wanted to have tests done to check her hepatitis C related health. She wants to have a brother or sister for her daughter as she believes her daughter gets lonely on her own.</td>
</tr>
<tr>
<td>Jocelyn</td>
<td>Jocelyn did not want to have any more children because she was almost 60 and was quite content with the two children she already had. Additionally, she had recently been very sick from hepatitis C.</td>
</tr>
<tr>
<td>Julie</td>
<td>Julie reported she would like to have children if the right guy came along to share the responsibility with. She also considered her financial situation to be problematic. Her hepatitis C related health was fine at the time of interview, however, she reported that this would be a consideration in relation to having children in the future.</td>
</tr>
<tr>
<td>Justine</td>
<td>Justine reported that she wants to have children once she had sorted out health, including having hepatitis C and being dependent upon methadone.</td>
</tr>
<tr>
<td>Karen</td>
<td>Karen did not want any more children because she had all she wants. This decision was not hepatitis C related.</td>
</tr>
</tbody>
</table>
Appendix 6: Summary of childbearing decisions and dilemmas and how they relate to hepatitis C continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Reasons and factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kylie</td>
<td>Kylie’s first child was in state care at the time of the interview and she was pregnant with her second child. She reported that she probably would not want to have any more children after the birth of her second child because of her hepatitis C related health. Additional factors were her reproductive health and her older age. She reported wanting to focus on mothering the children she already had.</td>
</tr>
<tr>
<td>Linda</td>
<td>Linda reported that she would like to have another child once she completes MMT. She wanted another child to strengthen her relationship with her partner. Linda had recently had two miscarriages. Her childbearing decisions were reported to be because of her hepatitis C and drug related health.</td>
</tr>
<tr>
<td>Lindsay</td>
<td>Lindsay reported that both she and her female partner wanted to each have a child (they planned to use a sperm donor, their flat mate, to help do this). Lindsay said that having children would make both she and her partner complete as individuals and as a couple. Hepatitis C was reported to be a significant consideration in having children, particularly in relation to having treatment.</td>
</tr>
<tr>
<td>Naomi</td>
<td>Naomi was undecided about whether or not she wanted to have another child and had given it some consideration recently. Her existing child was in the custody of his father’s custody. Naomi feared another child being taken from her because both she and her partner had mental health and drug dependence problems. She was concerned about the demands of motherhood and lack of support, as her family is in England and her partner’s family deceased. She reported that if she was going to have another baby, she should probably do it soon, otherwise she would be too old. Hepatitis C was not reported to be a major factor in her childbearing decisions.</td>
</tr>
<tr>
<td>Rebecca</td>
<td>Rebecca reported that she did not want any more children because of her dependence on heroin. She considered this, and the risks associated with hepatitis C to be unfair to a child.</td>
</tr>
</tbody>
</table>
Appendix 6: Summary of childbearing decisions and dilemmas and how they relate to hepatitis C continued …

<table>
<thead>
<tr>
<th>Name</th>
<th>Reasons and factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sally</td>
<td>Sally had decided not to have children because of her IDU, MMT, hepatitis C, the risk of vertical transmission, her older age and medical discrimination.</td>
</tr>
<tr>
<td>Sarah</td>
<td>Sarah did want any more children because of her older age. Once her son was born ‘nothing else matters’. Hepatitis C was a significant factor in her childbearing decisions, which was related to her age. She was also considering starting Interferon treatment, which would not have been conducive to having another baby.</td>
</tr>
<tr>
<td>Sharon</td>
<td>Sharon was a street-based sex worker with drug dependence problems. If she decided to have another child, she said she would check out her own hepatitis C related health first as well as finding out more about the risks of vertical transmission.</td>
</tr>
<tr>
<td>Sophie</td>
<td>Sophie reported that if she had children, she would do sex work to ensure the child had everything and that would not be a good situation to be in. Her hepatitis C and other health problems also factored into her decision not to have a child. However, hepatitis C alone would not prevent her from doing so. Additionally, she perceived there to be a lack of support for women with hepatitis C, and for this to make motherhood more difficult.</td>
</tr>
<tr>
<td>Theresa</td>
<td>Theresa has decided not to have a child because of her older age, having hepatitis C, other health problems, a lack of support and a lack of information about hepatitis C, especially in relation to childbearing. She feared her health would not live up to the demands of motherhood, and that becoming a mother would significantly reduce her life expectancy and quality of life. Emotional health problems also a factor. She had a child at age 15 who was forcibly taken from her at birth, and she continued to be very distressed about this.</td>
</tr>
<tr>
<td>Valerie</td>
<td>Valerie wanted to have children but had decided not to because of her hepatitis C, other health problems. She felt she had insufficient support to have a child, and that to do so would be expecting too much from her aging mother.</td>
</tr>
<tr>
<td>Veronica</td>
<td>Veronica was happy about her current pregnancy because she wanted another child before she became too old. Her partner also wanted a child but she had doubts about his ability to cope as a father. Hepatitis C did not appear to be a major factor in her childbearing decisions.</td>
</tr>
</tbody>
</table>
Appendix 7: Participant profiles

Abby

Abby is in her mid-20s and currently living in a bed-sit with her partner. Abby has experienced some symptoms of hepatitis C, although she estimates her infection to only be two years in duration. She is unable to fully distinguish these symptoms from the malaise she experiences as a result of her drug dependence.

Abby is currently pregnant and looking forward to the birth of her second child. She is, however, concerned about how having hepatitis C will affect her baby. Now that she is pregnant she has found there to be insufficient information available to her regarding how hepatitis C could affect her baby.

Upon discovering she was pregnant, she stopped injecting drugs and started methadone maintenance. She made the same requirement of her partner, who is also dependent on heroin. She has also made it clear to him that he must stay out of jail and off drugs in order that this baby is not removed from their care. She also wants to try to regain custody of her first child who is currently in the custody of her ex-partner, the child’s father.

Abby’s middle-class family have rejected her because of her drug use and her association with men who always seem to end up in prison. Her only sources of support are from her current partner and his mother.

Abigail

Abigail discovered she was hepatitis C positive when she was pregnant with her first child, who was born a few weeks prior to the interview. She has experienced some mild hepatitis C symptoms. Her main concern is that her baby does not contract hepatitis C from her.

Abigail had injected drugs at the beginning of her pregnancy but was meticulously careful to avoid risks of infection. When she discovered she was hepatitis C positive she was very disappointed because she had been so careful to avoid it.

Abigail is currently living with her mother in an inner city suburb and is in contact with the father of her child. She thinks she contracted hepatitis C through sharing injecting equipment with the father of her baby, who she describes as ‘needy’ because of his drug dependence.
Amy

Amy has seven children, six of whom live with their father and the eldest lives with her. She gets to see her children on school holidays when they can go to her house. Because she no longer has her children with her at home, she goes into the city and Kings Cross each day to spend time with her friends on the street and at services such as the Kirkton Road Centre.

Amy is distressed because her ex-husband uses her IDU and hepatitis C to discredit her to her children. She spends most of her time with other injectors who live on the street in Kings Cross. Her health is poor, largely because of her drug dependence and her five-year hepatitis C infection has made her health worse. She contracted hepatitis C by sharing injecting equipment with someone who had recently been released from prison.

Becky

Becky is currently a sex worker, and lives in a comfortable home in an Inner Sydney suburb. She came to live in Australia from the UK several years ago and married an Australian man. When she was diagnosed with hepatitis C, she believed she was going to die early and would never be able to have children. This contributed to her divorce from her abusive husband, who blamed her for acquiring hepatitis C and not being able to have children.

Becky has since discovered that she is unlikely to die of hepatitis C any time soon and that her hepatitis C should not in itself prevent her from having children. She is also stable on a methadone programme. She is considering undergoing treatment for her hepatitis C but she has a dilemma: because she has had fertility problems relating to her use of contraceptives, she is reluctant to use them again. However, it is a condition of the hepatitis C treatment that patients use two forms of contraception, and although she has not yet discussed this with a doctor, she is very concerned about it.

At the time of the interview Becky believed she would not be able to have a child for some time. However, about a year after the interview I met Becky and she had a healthy baby.
Dawn

Dawn is in her mid-30s and happily married to her long term partner. They have fought their drug dependence together and are both doing very well on methadone maintenance. At the time of interview, Dawn was pregnant with her second child. Her first child is a healthy eighteen month old.

Dawn and her husband were very concerned about hepatitis C in relation to childbearing, particularly so because they are both hepatitis C positive. When they decided they were ready to have children, they set about investigating the risks associated with hepatitis C. They sought information from a range of people they considered to be most knowledgeable.

They are satisfied that hepatitis C presents few problems to their childbearing and parenting. Their greatest concerns revolve around their being on methadone and what this means for their new baby, as well as the social impact it has, such as the involvement of social services at the antenatal hospital.

Ellie

Ellie is in her late 20s and despite her drug dependence, is employed full time in a job she enjoys very much. She lives in a salubrious suburb of Sydney with her mother and ex-boyfriend.

Generally her health is good and she is quite stable on her methadone program, although she does regularly inject her methadone. She has experienced some nasty symptoms she attributes to the acute stage of hepatitis C, but most of the time she feels fine.

Ellie wants to have children one day, when she meets the right man to share the parenting responsibility with. Her concerns relate to her own health rather than the risk of vertical transmission. She is concerned about whether or not she will get sick and be unable to care for her children. Before she considers having children, she is determined to get her drug dependence under control.
Emily

Emily is in her late 30s and lives with her long term partner and 10 year old son. She is currently injecting but her overall health is pretty good and she doesn’t really experience any hepatitis C symptoms. She has a limited number of people she can call on for support, and wishes she had more.

When Emily had her son in a western Sydney hospital 10 years ago, she was ‘treated like a leper’ because she had hepatitis C and was a drug-using mother. Her son experienced withdrawal problems after birth and required medication. She has not had her son tested for hepatitis C but she does have some concerns that she he may have acquired hepatitis C from her.

She doesn’t expect she will have any more children because of her partner’s older age and poor health, as well as her own older age. She feels they would be unable to give another child a good quality of life. Emily wishes she could have had more children but feels it is now too late.

Fiona

Fiona is in her early 20s and her world has been thrown upside down by hepatitis C. She experiences severe lethargy and struggles to keep up with her TAFE course. She feels that hepatitis C has an enormous impact upon her holistic health as well as her physical health.

Fiona recently had a termination, which she attributes largely to having hepatitis C, both directly and indirectly. She was concerned about the risk of vertical transmission, and felt she would not be able to cope with a child emotionally, physically or financially because she has hepatitis C. Her problems seemed even greater because she felt she lacked support.

Fiona is very fearful of the effects of the stigma associated with her hepatitis C. She has been rejected by some of her family and friends because she has hepatitis C, mostly because they perceived it to be highly infectious. She fears that if she discloses her hepatitis C to her current housemates they too may reject her because of the IDU associated with the virus, as well as being infectious.
Gemma

Gemma is reasonably stable on a methadone program and had recently stopped doing street-based sex work and living on the street. Her partner has severe drug dependence problems and lives a very chaotic life.

She has one child who is in State care. Her child was removed from her custody after her doctor and child protection authorities deemed her an unfit mother. Her partner, the father of her child, has another child who is also in State custody. They have very limited supervised contact with their children. Gemma ultimately aims to regain custody of her daughter but knows she has to meet certain criteria to be able to do so.

Gemma feels that having hepatitis C has driven her out of the workforce, as she is unable to work because of the symptoms she attributes to her hepatitis C. She also feels that her relationships with people are limited because she has hepatitis C. She does not disclose her hepatitis C to others because she fears rejection because of it. However, because she has to keep things secret from people, she feels this restricts the depth and intimacy of her relationships with other people.

Georgia

Georgia is 40 years old and lives with her partner in a wealthy suburb of Sydney. She works full time with children in a responsible position. She injects regularly but is very stable on her methadone program.

Georgia wants very much to have a child with her partner. However, he has some reservations because they both have hepatitis C and is concerned about the risk of vertical transmission. He is also concerned that they may become sick and not be able to adequately care for their children. Georgia suspects that he will come round over time and they will have children. She feels having children is an important aspect of cementing their relationship, and that she would make a good mother. Interestingly, Georgia believed the risk of vertical transmission to be four times greater than what it actually is, and she deemed this to be an acceptable risk.
Hannah

Hannah is happily married and in her late 30s. She lives in an affluent eastern suburb of Sydney and works in a semi-professional occupation. She used to inject illicit drugs over twenty years ago and now feels she is paying the price because she has hepatitis C.

She has changed her lifestyle considerably after being diagnosed with hepatitis C, with the help of her very supportive husband. She thinks she is currently pregnant and is happy about this, although she does have some concerns that she may not make a very good mother, as she says she is not very ‘maternal’.

She would have liked to have been able to delay childbearing and have treatment for her hepatitis C first. However, she feels that she is too old to be able to do this. If she were to have treatment, she would take some time to recover, by which stage she feels she would be too old to have children.

Janice

Janice is in her early 40s and lives with her two children and her ex-husband in a salubrious Sydney suburb. She has a large network of friends who are injectors, many of whom have hepatitis C.

Janice has not really experienced any symptoms of hepatitis C and doesn’t consider it to limit her ability as a mother or employee. Janice still injects sometimes but also keeps very fit and healthy.

Janice is very aware of the negative social perception of drug-using mothers and is anxious to dispel the stereotypes. She is sensitive to the potential negative consequences of disclosing her hepatitis C and injector status, and as a result has a policy of non-disclosure unless it is absolutely necessary. She feels she has two separate lives: that of an injector, and that of a caring, responsible mother. This is because she feels she cannot share her hepatitis C and injector status with non-injectors because of the stigma attached to it.
Jean

Jean is single and in her mid-40s and lives with her teenage son in an inner city suburb. She had hepatitis C at the time she gave birth to her daughter but at the time it was known as non-A non-B hepatitis. Her son has never been tested for hepatitis C, although Jean believes he does not have it. Although she would quite like to have another child, she considers herself to be too old and is very concerned about how hepatitis C would affect a baby, in particular, the risk of vertical transmission.

Jean experienced severe symptoms from hepatitis C several years ago and was hospitalised for some time. While she was in hospital, her partner at the time cared for her son. If she did not have her partner to care for both she and her daughter, she does not know how she would have coped. Jean is very concerned about her future health because she has hepatitis C.

Jean injects occasionally and has good networks of friends who are mostly injectors. She also has friends who work with the Hepatitis C Council. She does not have much contact with her family as they live overseas so she relies quite heavily upon her friends when she is in need of support, especially now that she does not have a partner.

Jessica

Jessica is originally from the UK, and in her early 30s. She lives with her daughter and her partner, who also has hepatitis C. She has never injected drugs and finds it frustrating that most people assume that she has done because she has hepatitis C. Jessica does not know how she caught hepatitis C. She has been with her partner for several years and has always been aware that he has hepatitis C, and as a result were very careful to avoid transmission risks.

Jessica experienced problems with immigration coming into Australia because she has hepatitis C and had to enlist the help of specialist medical professionals to assure immigration that she did not pose a risk of infection to others. Although she has been in Australia for a couple of years, she does not have any good friends and feels quite lonely. She has very limited sources of support as all her family are in the UK.

Jessica and her partner want to have a child soon. However, she is very concerned about the risk of vertical transmission and wants to do everything possible to reduce the chances of vertical transmission. She feels she needs more information, particularly about her own health condition relating to hepatitis C, in order to make an informed decision. All the information Jessica wants is unavailable, so she is using alternative therapies and living as healthy a lifestyle as possible in order to reduce the risk of vertical transmission before she becomes pregnant.
Jocelyn

Jocelyn is originally from Europe and at almost 60 is the eldest woman in the sample. She is also the only woman in the sample to have received any treatment for hepatitis C. Jocelyn has been very sick from hepatitis C over the last couple of years and at the time of interview had just been released from hospital after several months.

She has had to give up work because of the severe symptoms she experiences from hepatitis C. She has found that hepatitis C has plunged her into poverty, which she cannot see an end to. Because she is unable to work she is dependent on state benefits, however, the cost of her medications and trips to the hospital use up a great proportion of what little money she has.

Jocelyn has two children, who are in their early twenties and in higher education, one of whom lives with her. She knows that it is very difficult for her children to see her so sick, and it’s even worse when people say she is to blame for her health problems because she used to inject drugs, even though it is over 25 years since she last injected. Jocelyn finds dealing with the stigma associated with hepatitis C, particularly regarding IDU, very draining and frustrating.

Julie

Julie is in her early 30s and lives with her boyfriend who has his own drug use problems. She is reasonably stable on her methadone program, but continues to inject regularly. Julie reports enjoying good general health, but she did experience some jaundice around the time when she suspects she contracted hepatitis C.

Julie wants to have children once she is in a relationship with a man she feels would make a good partner and father. However, she has concerns regarding disclosure of her hepatitis C to non-drug-using friends and potential partners. This restricts her ability to move outside of injector social circles and develop new strong friendships and relationships with non-injectors.
Justine

Justine is in her mid-30s and has severe drug dependence problems. She has a flat in an inner city suburb and has recently stopped working in the sex industry because she experiences severe lethargy from her hepatitis C, which she combats with amphetamine use, which ultimately leaves her feeling worse.

Justine would like to have a child once she manages to improve her health and gain control of her drug dependence. However, she avoids contact with medical professionals because she fears they will judge and discriminate against her because she has hepatitis C and is an injector. She expects this to be a major problem when she is ready to have children, as being pregnant and having a baby always involves some medical involvement.

She is also very concerned about the lack of knowledge on the effects of hepatitis C upon children and the risk of vertical transmission. In particular, she expects that obstetricians would have little understanding and knowledge of hepatitis C and IDU, which would result in more discrimination and a great deal of anxiety.

Karen

Karen is in her mid-30s and lives with her husband and three children. She has never injected drugs and does not know how she contracted hepatitis C. She has never experienced any symptoms from hepatitis C and was very shocked when she was diagnosed with hepatitis C. She reported she intends to have her children tested for hepatitis C, as she has not done so yet. Karen does not want any more children. This is not because she has hepatitis C but because she already has three children and does not want to have more at her age.

She was diagnosed with hepatitis C about a year ago and at the time of interview was about to have a biopsy to determine whether or not to undergo treatment for her hepatitis C. She will have the treatment if the doctor recommends it because she wants to do it while she is still young and strong enough to cope with it, as well as being a mother to her children.

Karen has been discriminated against in her workplace because she has hepatitis C. She believes that was because hepatitis C is infectious and that her colleagues perceived her to be a sick person, who would be unable to work, as well as being a reminder to others of their own mortality.
Kate

Kate is a professional woman in her mid-30s and happily married to her long term partner. She has never injected drugs and suspects her hepatitis C infection to be from a medical procedure in the 1980s. She has two young children and hopes to have a third soon, depending upon her own hepatitis C related health and whether or not both her existing children are free from hepatitis C.

Kate has been discriminated against because she has hepatitis C, particularly in medical settings when she was having her children. She was also advised to abort her second child by an obstetrician, she believes, because she has hepatitis C.

Kate is trying desperately to do everything she can to minimise the risk of vertical transmission to their third child, she and her partner are planning to have. She wants more information about the risks associated with childbearing and hepatitis C and has consulted several hepatologists and internet-based resources.

Kath

Kath is a mother to two children and is pregnant with a third child. She has drug dependence problems and has continued to inject and drink a lot of alcohol throughout her pregnancy. She has not been attending regular antenatal care, and the care she has received has been interrupted because she has moved from one side of the city to another.

She is concerned about the risk of vertical transmission to her baby but expects everything should be okay. She does not want to be blamed for her child having hepatitis C. This fear of being blamed is what drives her to openly disclose her hepatitis C status in order to avoid infecting anyone else. She has a supportive mother and partner. However, her partner also has severe drug dependency problems.

Kath experiences some symptoms of hepatitis C, which are sometimes very painful and is very aware of how severe it can be because her brother, who is now deceased, experienced serious debilitating symptoms from hepatitis C.
Kelly

Kelly is in her late 20s and lives with her ex-partner and two children in a Southern Sydney suburb. She has to travel by train into the city to attend for her hepatitis C related health care. She also has to arrange childcare for these trips into the city, as it would be almost impossible to bring two small children with her.

Kelly was diagnosed with hepatitis C when she was pregnant with her second child four years ago. She was diagnosed late into her pregnancy and she was very concerned that she would infect her baby. Because it was too late to terminate the pregnancy and her first child tested negative for hepatitis C, she decided that the odds were in her favour and both her children are healthy. Kelly did not receive pre or post-test counselling and was not asked for her permission to test for hepatitis C. She is constantly worried about transmitting the virus on to her children.

Kelly stopped injecting drugs about three years ago. Although she was shocked when she was diagnosed with hepatitis C, she was not totally surprised because she had been an injector. She experiences hepatitis C symptoms and these are sometimes debilitating. She is concerned about her future health because of her hepatitis C but is confident that her children will be well cared for by her family if she becomes very sick or even dies.

Lindsay

Lindsay is in her late 20s, and lives with her female partner and a flatmate in Sydney’s west. Lindsay purposefully infected herself with hepatitis C by sticking a used needle belonging to her partner into herself. She did this to demonstrate her love for the woman who is now her partner. Although she describes many negative aspects of having hepatitis C, she believes she made the right decision to knowingly infect herself because she is now with the person she loves as a result.

Both she and her partner would like to have a baby each, which they would bring up together. However, her partner is older than Lindsay and is often quite sick from hepatitis C. They plan for their male flatmate to be the father of their children.

Lindsay’s family have rejected her because they assume her to be an injector because she has hepatitis C. Although Lindsay has injected drugs before, she does not believe she is a stereotypical ‘junkie’, but her family have rejected her on this basis.

Lindsay has experienced much discrimination because she has hepatitis C, from family and medical professionals, as well as others. Some of this discrimination was because of a perceived high risk of infection and some because of the association between hepatitis C and IDU.
Linda

Linda lives with her 10 year old son and her partner. She is in her early 30s and has a very supportive family who live close by. She was diagnosed with hepatitis C five years ago and experiences debilitating symptoms that compound the health problems she experiences through her drug dependence. Both she and her partner are on methadone and go into the city each day for their dose. She still injects sometimes as well but is determined to get off methadone as soon as she can. She cannot work because of her poor health, largely because of the lethargy she experiences daily. She also reported feeling frustrated because she often does not have enough energy to do things like taking her son to the park.

Linda’s son is very aware of the dangers associated with injecting. He knows that his mother and his step-dad have hepatitis C and he is not to touch anything of theirs such as their toothbrush or razor. Linda split up with her ex-partner because she felt he presented a danger to her son, as he was not careful enough with injecting equipment around him.

Linda has had two miscarriages recently, one of which her obstetrician partly blamed on her methadone use. She wants to have another child with her current partner, but not until they have finished their methadone program and are healthy.

Kylie

Kylie has been pregnant seven times. She has one child and was pregnant at the time of interview. She has had four terminations and one miscarriage. Kylie is on methadone maintenance, and injects it occasionally. She is concerned about this because she does not want her baby to experience withdrawal symptoms.

Kylie’s existing son is in long term foster care and she rarely gets to see him. Her son was removed from her care a year ago because of the domestic violence her partner continues to inflict upon her. Kylie attempted suicide when they took her son away from her. She is determined not to allow this to happen again, but he continues to be violent towards her when he is drunk. They have agreed to split up if their problems continue and affect their new baby.

Kylie does not expect to have another child after this one, mainly because she is getting too old and her poor health. However, if she does have another baby, it will be quite soon after this one is born so that she has it while she is younger. Her concerns about hepatitis C and childbearing are outweighed by her methadone use whilst pregnant, and the physical abuse from her partner.

Kylie was diagnosed with hepatitis C two years ago. She has not really experienced any symptoms she attributes to hepatitis C but she does feel as though she is not very healthy at the moment. She attributes her poor health to her long term use of methadone.
Naomi

Naomi is in her late 30s and moved to Australia from the UK several years ago. She has drug dependency and mental health problems. She has a daughter who is in the custody of her ex-partner, who is her daughter’s father. Her ex-partner used her mental health and drug use problems to gain custody of their daughter.

Naomi has no family in Australia and her partner’s parents are both deceased. She and her partner only have each other for support. Her partner has severe drug dependency and significant mental health problems.

Naomi’s health is poor at the moment and she attributes much of this to being on methadone. She does not have any hepatitis C symptoms that are distinguishable from the malaise she experiences because of her drug dependence and methadone use.

Naomi said she probably wouldn’t have another child because of her mental health condition and her drug dependence. Also, she feels her partner would not be able to cope with the responsibilities of parenthood. However, she would like to have another child and if she did decide to go ahead, it would be sooner rather than later as she feels she is getting too old to start motherhood again.

Sally

Sally is in her late 30s and regularly injects drugs. She has a large network of friends who are injectors, many of whom have hepatitis C.

Sally has lived with hepatitis C for more than a decade and sometimes experiences mild symptoms, but manages to work full time. Fortunately, her workplace is flexible and sympathetic to her needs. Being on methadone, she has trouble differentiating hepatitis C symptoms from those relating to her drug dependence.

Like many other women with hepatitis C, she avoids seeing doctors and dentists because she fears judgmental attitudes and discrimination. These fears are based on her past experiences and the many reports from other people of similar experiences. The only people she discloses her hepatitis C and injector statuses to are involved in her drug related health care, such as her methadone prescriber.

She has decided to remain childless because of her drug use, being on methadone, concern about vertical transmission and her financial status. Overall she perceives her lifestyle is not conducive to good mothering and if she were a bad mother she would feel very guilty. She has come to this decision over a long period of consideration, with many episodes of confusion and doubt.
Rebecca

Rebecca is in her late 30s and lives on the street and in motels around Kings Cross. She does sex work on the streets to pay for her drug use. After previously being in a physically abusive marriage, she is now a lesbian but is currently single.

Rebecca has a son who is now adult and has a child of his own. She would not consider having another child because of her drug dependence and street-based life. She thinks that having children when using drugs is morally wrong because babies should not be put at risk of drug dependence and viral infections, such as hepatitis C. Rebecca has been in and out of prison for much of her adult life. Each time she was in prison her partner or family would care for her son.

Rebecca and her husband have strict rules, regarding the wellbeing of their son, which they have adhered to. They never allowed him to be exposed to their drug use, nor would they defame each other to him. Rebecca has not attended for much needed medical attention because her drug dependence is so severe – she fears withdrawing whilst in hospital and does not want to be put on methadone when she is in there.

Sarah

Sarah is in her mid-40s and happily married to her husband. She lives with her husband and newborn baby in a wealthy suburb close to the city. Like her own family, they live a comfortable middle-class lifestyle.

Sarah assumes she became infected with hepatitis C somehow when she was an injector over 20 years ago. She does not experience any severe symptoms from hepatitis C but does attribute her lethargy to it. Sarah is currently undergoing tests to determine whether or not she should have treatment for her hepatitis C.

Her husband is very supportive, but he expressed concern about the risk of vertical transmission when they were discussing their desire to have a child. He was not sure if it was immoral to risk having a child born with hepatitis C. Sarah convinced him that the risk was sufficiently low and that having a child was worth taking the risk.

Sarah was warned by her obstetrician that if she breastfed she would never know if she could have done anything to prevent her child from becoming hepatitis C positive. Consequently she did not breastfeed because she could not face the prospect of being in any way blamed for her child having hepatitis C. As yet she has not had her child tested for hepatitis C as it is too early for any tests to be conclusive.

Sarah’s friends were very surprised when she told them she has hepatitis C because she does not fit the stereotype of the kind of person who has hepatitis C. Her characteristics conflict with those associated with the stereotypical junkie who usually has hepatitis C.
Sharon

Sharon is in her mid-30s and lives in a bed sit in Kings Cross. She works as a sex worker on the streets of Kings Cross in order to fund her drug use.

Sharon has a teenage daughter who is being cared for by Sharon’s own father in Queensland. She was not sure if she had hepatitis C at the time of her birth. She does not want to have any more children because of her drug use, sex work and the risk of vertical transmission of hepatitis C.

She experiences painful and severely debilitating symptoms from hepatitis C. These are exacerbated by her health problems associated with her drug use and generally not taking very good care of herself.

Sharon is very dependent on the range of services targeted at street based injectors in Kings Cross and values them highly. She feels she can be very open about her drug use and hepatitis C around Kings Cross because there are so many other people like her there.

Sophie

Sophie is in her mid-20s and has decided to remain childless for several reasons. She has other health problems, which pose more of a concern to her regarding childbearing than hepatitis C. The risk of vertical transmission would be a concern for her, but would not in itself prevent her from having children. Sophie reported that if she were a mother she would be doing sex work in order to ensure they had everything they need. This, she believes, is not a good situation in which to bring up children.

Sophie has not injected drugs for several years but knows many people who inject and who have hepatitis C. She also works with people who have HIV/AIDS as well as hepatitis C and was able to speak from a personal as well as professional perspective.

Sophie has a good network of support through work and friends as well as from her mother. She is confident about her decisions to not disclose her hepatitis C status in order to prevent discrimination.
Tammie

Tammie is in her late 40s and injects regularly but is very stable on her methadone program. She has a strong network of friends who work with injectors and people living with hepatitis C and HIV/AIDS. She has very good access to official sources of information and advice as well as that provided by her strong social network. This she feels has made her considerably more confident and more able to assert her rights, particularly in a medical setting where she has previously felt intimidated. She believes that the discrimination she has experienced has largely been because she is an injector, rather than because she has hepatitis C.

Tammie has experienced severe and debilitating symptoms from hepatitis C in the past, although she rarely experiences any now. However, because she has been so sick from it in the past, she is very fearful of becoming very sick again in the future. She is also very wary about the negative side effects from hepatitis C that are currently available, which prevents her from seeking treatment.

Tammie has decided that she will remain childless. She feels she is now too old to begin childbearing, and has no desire to become a mother.

Theresa

Theresa is in her early 40s and is a successful businesswoman, who works full time in a very demanding job. She has also had hepatitis A and B in the past and experiences moderate symptoms of hepatitis C. She finds that she has to manage her time carefully in order to cope with her work and not become overly fatigued.

Theresa has recently come to the decision that she will remain childless for several reasons, but most of them are closely related to her hepatitis C related health. She is very worried that her health would not be able to cope with pregnancy and the demands of motherhood. She is concerned for her own wellbeing and also what her poor health would mean to a child and her partner.

Theresa has grave concerns about the risk of vertical transmission. She considers women with hepatitis C who are having children to be ‘human guinea pigs’ at present, given the lack of knowledge of risk factors that may exist to affect the risk of vertical transmission occurring.

Theresa has also had a baby when she was a teenager, but the child was removed from her by her parents and given up for adoption. This has been the cause of a great deal of distress for a long time, and she feels may in some way have impacted upon her decision to not have another child. Because she has not had any contact with her child, this means that she will remain essentially childless.
Valerie

Valerie is almost 40 years old and lives with her mother in a Western Sydney suburb. She is now stable on a methadone program and has stopped working in the sex industry as she has managed to control her drug use.

Although Valerie was a past injector, she reported that the source of her hepatitis C infection was a medical procedure performed overseas. She is confident about the source of her infection because she tested positive for hepatitis C before she began injecting illicit drugs.

Valerie has decided to remain childless because she feels her health problems are too great and she is now too old to begin childbearing. She also feels she is not in a position to be able to care for a child because she has a lack of support, and her financial situation is now dire due to her drug dependence. Because she struggles to manage the symptoms she experiences from hepatitis C, she believes she would not be able to work to improve her financial status and has serious concerns that she would not be able to cope with the physical demands of childbearing and motherhood. Valerie believes that it would be selfish of her to have a child under these circumstances.

Veronica

Veronica was pregnant with her third child at the time of interview. Although she has not tested her children for hepatitis C, she believes them to be healthy and that they do not have hepatitis C. She does, however, attribute the small size of her daughter to her methadone use whilst pregnant. She has been advised that the risk of vertical transmission is small and she has decided that this is acceptable.

Veronica lives with her two children and her partner, who is not the father of her two children. She reported her partner to have some serious emotional problems and that it is not unusual for him to be physically abusive to her.

Veronica injects her methadone sometimes but is reasonably stable on a methadone program, and has tried not to inject at all since she discovered she is pregnant. She had planned to stop taking methadone, or at least reduce her dose, before she became pregnant but was advised not to do so whilst pregnant so she has delayed doing so until after her baby is born.
This project is designed to learn more about how women are living with hep C and in particular how it affects their parenting decisions.

We are also interested to learn more about the health and other support services that are available and how they might be improved to make childbirth and parenting easier for hepatitis C positive women and their families.

The research will identify problems faced by women with HCV and in particular, those problems relating to motherhood. It will also examine the health, social and support services available to these women. In identifying and analysing these issues, service providers and policy makers will be better placed to address these issues, and so improve the services available to these women in the future. Hepatitis C is a growing problem and hence such research is necessary to understand the problems that it creates for individuals as well as different social groups.

You will be asked to take part in one interview, lasting between approximately 45 to 90 minutes. You will be asked about different aspects of your life, some of which may not seem to be directly related to hepatitis C. These questions will be about your relationships and other social issues, your economic security, your health, your feelings on different issues concerning hepatitis C and childbearing and children.

The interviews will be recorded on tape, but will not be made identifiable with your personal details. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. If you give us your permission by signing this document, we plan to discuss the results with colleagues at conferences and other meetings, and to publish the results in peer-reviewed journals and other reports. The results may also be posted on our Internet website, or appear in the media. No real names or other means of identification will be used in such cases.

A financial reimbursement of $25 will be paid upon completion of the interview, for which you will be required to sign a form to confirm that you have received this money for this purpose. Again, your details will not be associated with the information in the tapes. If you wish, you can provide a false name.
If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice. Additionally, if there are any questions you do not wish to answer for whatever reason, you are free to refuse to respond, and continue with the rest of the interview should you so wish.

Please contact Clare Thetford (researcher) on 0412 121 959 or clare@coombs.anu.edu.au who will be happy to answer any questions you may have about the research project.

You will be given a copy of this form to keep.
You are making a decision whether or not to participate. Your signature indicates that, having read the information provided above, you have decided to participate.

_______________________  _______________________
Signature of participant    Signature of researcher

_______________________   _______________________
Please print name    Date
(You may give a false name)

Participant ID:

Any complaints should be directed to the Australian National University Human Research Ethics Committee: Human.Ethics.Offer@anu.edu.au

Research Services Office
Chancelty 10B
The Australian National University
ACT 0200
Tel: 02 6125 2900
Fax: 02 6125 4807
Appendix 9: Copy of questionnaire

Hepatitis C and Childbearing: Questionnaire

The following questions are to allow me to make some basic comparisons and to help me to ask you questions that are most appropriate. If you are not sure how to answer any question please ask the interviewer to explain. If there are any questions you do not wish to answer for whatever reason you can simply leave them out.

Date of birth: / / 

Ethnicity (as you perceive it):

Religion (which religion and if you consider yourself to be practising):

Country of origin (if not born in Australia):

Is English your first language?

Occupation:

Are you currently working?

If yes, is this part time or full time?

Approximate annual income before tax:
$1 - $9,999 □
$10,000 - $19,000 □
$20,000 - $29,000 □
$30,000 - $49,000 □
$50,000 - $69,999 □
$70,000 - $99,999 □
$100,000 or more □
None or negative income □
Don’t know □

If you wish to include your partner’s income, please state:

What is your current living situation? Tick box.
   a) Live in own home □
   b) Rent home □
   c) Lodge □
   d) Other (please describe):
Who do you live with? For example, your partner, parents or children (names not required).

Postcode:

What is the highest level of education you have completed?

Do you know how you caught hep C? If yes, please indicate how:
   Yes □
   No □

Do you currently inject illicit drugs?
   Yes □
   No □

Have you ever injected illicit drugs? If yes, please provide approximate date on which you last injected.
   Yes □ / /
   No □

Do you have private health insurance?
   Yes □
   No □

How do you describe your current state of health? Eg., good, fair, poor
Appendix 10: Interview schedule

Hepatitis C and Childbearing: Interview Schedule

Hepatitis C and health
- How did you feel when you were diagnosed as having hep C?
- How long ago do you think you caught hep C?
- How do you think you caught hep C?
- Drug use? Current user, occasional, never?

Relationships and support
- Who have you told you have hepatitis C?
- How many other people do you know who have hepatitis C?
- Where do you get information and advice about hepatitis C?
- Has anyone reacted badly when you told him or her you have hepatitis C?
- How did your family react when you told them you have hepatitis C?
- How did your partner react if you told them you have hepatitis C?
- Does your partner have hepatitis C?
- Do you feel you have suffered discrimination because of your hepatitis C status? If so, by whom?

Standard of life
- Since you found out you have hepatitis C is your life better, worse or no change?
- What are your concerns for the future regarding having hepatitis C?
- Have you ever received treatment for hepatitis C? What?
- Are you currently receiving treatment for hepatitis C? What?
- How would you describe your current state of health?
- Do you have any serious symptoms of hepatitis C? What are they? When was this diagnosed?
- How does having hepatitis C affect your every day activities, if at all?

Childbearing
- Do you have any children? How many and ages?
- How many children would you like to have (if any)?
- Are you currently pregnant?
- Was the pregnancy planned? When did you make this decision?
- Who and what are important to you when considering whether or not to have a child or more children in addition to existing ones?
- Are you planning to become pregnant in the near future?
- Has having hepatitis C changed your views on your own childbearing?
- As a mother, do you face any extra difficulties because you have hepatitis C? What are they?

End
- Is there anything that you consider to be important or relevant that we have not discussed?
Appendix 11: Data coding scheme

Each of the code words used is defined below. The hierarchical position of each of the codes is displayed in appendix 12.

<table>
<thead>
<tr>
<th>Code word</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abortion</td>
<td>Experience of termination of pregnancy</td>
</tr>
<tr>
<td>Acutesympt</td>
<td>Experience of acute stage symptoms</td>
</tr>
<tr>
<td>Age</td>
<td>Age in years and the effect of this upon childbearing decisions and motherhood</td>
</tr>
<tr>
<td>Alttherapy</td>
<td>Use of alternative therapies for hepatitis C</td>
</tr>
<tr>
<td>Anysymptom</td>
<td>Experience of any hepatitis C symptoms</td>
</tr>
<tr>
<td>Auxtraits</td>
<td>Auxiliary traits: characteristics people are assumed to have based upon a social label that has been successfully applied to them.</td>
</tr>
<tr>
<td>Badmum</td>
<td>Being labelled as a bad or unfit mother based upon assumed or actual characteristics</td>
</tr>
<tr>
<td>Birth</td>
<td>The experience of childbirth and related issues</td>
</tr>
<tr>
<td>Blame</td>
<td>Blame associated with stigmatised conditions and deviant behaviour</td>
</tr>
<tr>
<td>Breastfeed</td>
<td>Breastfeeding related issues and experiences</td>
</tr>
<tr>
<td>C-section</td>
<td>The role of mode delivery in reducing the risk of vertical transmission of hepatitis C</td>
</tr>
<tr>
<td>Childbeari</td>
<td>Experience of childbearing decisions and childbearing</td>
</tr>
<tr>
<td>Childdiscl</td>
<td>Decisions about and experiences of disclosing hepatitis C to own children</td>
</tr>
<tr>
<td>Childtest</td>
<td>Decisions about and experiences of testing children for hepatitis C</td>
</tr>
<tr>
<td>Concerns</td>
<td>Most important concerns regarding hepatitis C</td>
</tr>
<tr>
<td>Costhealth</td>
<td>The cost of hepatitis C related health care</td>
</tr>
<tr>
<td>Currsympto</td>
<td>Experience of current or intermittent hepatitis C symptoms</td>
</tr>
<tr>
<td>Custody</td>
<td>Experience of not being in custody of own children</td>
</tr>
<tr>
<td>Desfamsize</td>
<td>Desired family size</td>
</tr>
<tr>
<td>Desirechil</td>
<td>Reasons for wanting to have children</td>
</tr>
<tr>
<td>Deviance</td>
<td>Deviance through behaviour or possessing an objectionable trait</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Experience of diagnosis of hepatitis C</td>
</tr>
<tr>
<td>Disclosure</td>
<td>Considerations and experiences of disclosing hepatitis C</td>
</tr>
<tr>
<td>Discrcredit</td>
<td>Negative experiences of being socially labelled and stigmatised</td>
</tr>
<tr>
<td>Docpatrel</td>
<td>Doctor-patient relationship.</td>
</tr>
<tr>
<td>Docshoppin</td>
<td>Experiences of doctor shopping to obtain required health care</td>
</tr>
<tr>
<td>Drugdepend</td>
<td>Experiences of being drug dependent</td>
</tr>
<tr>
<td>DUP</td>
<td>Experiences of drug use during pregnancy</td>
</tr>
<tr>
<td>Duratinfec</td>
<td>Duration of hepatitis C infection</td>
</tr>
<tr>
<td>Education</td>
<td>Level of education attained</td>
</tr>
<tr>
<td>Emotionalh</td>
<td>Emotional health issues</td>
</tr>
<tr>
<td>Employment</td>
<td>Employment related issues</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Ethnic group</td>
</tr>
<tr>
<td>Existchild</td>
<td>Experience of mothering children and how existing children impact upon childbearing decisions</td>
</tr>
<tr>
<td>Factors</td>
<td>Factors involved in childbearing decisions</td>
</tr>
<tr>
<td>Family</td>
<td>Experiences of relationships with their family</td>
</tr>
<tr>
<td>Code word</td>
<td>Meaning</td>
</tr>
<tr>
<td>-----------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Father</td>
<td>Role of father: expected role and experiences of sharing parenting responsibilities with father of children</td>
</tr>
<tr>
<td>Financial</td>
<td>Financial situation, income and related issues</td>
</tr>
<tr>
<td>Friends</td>
<td>Experiences of relationships with friends</td>
</tr>
<tr>
<td>Gender</td>
<td>Gender-related issues</td>
</tr>
<tr>
<td>Guilt</td>
<td>Experiences of feeling guilty</td>
</tr>
<tr>
<td>HCVgeneral</td>
<td>General issues surrounding hepatitis C</td>
</tr>
<tr>
<td>HCVhcare</td>
<td>Hepatitis C health care</td>
</tr>
<tr>
<td>HCVpercept</td>
<td>Perceptions and experiences of living with hepatitis C</td>
</tr>
<tr>
<td>Health</td>
<td>Overall condition of health</td>
</tr>
<tr>
<td>Healthcare</td>
<td>General health care</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>Perceptions of HIV/AIDS. Similarities and differences between HIV/AIDS and hepatitis C</td>
</tr>
<tr>
<td>Holistiche</td>
<td>Perceptions of holistic health</td>
</tr>
<tr>
<td>Housing</td>
<td>Experiences of housing situations</td>
</tr>
<tr>
<td>Hsholdtrans</td>
<td>Perceptions and experiences of managing the risk of household transmission of hepatitis C</td>
</tr>
<tr>
<td>IDU</td>
<td>Experiences surrounding injecting drug use and related issues</td>
</tr>
<tr>
<td>Income</td>
<td>Issues relating to income</td>
</tr>
<tr>
<td>Infertilit</td>
<td>Experience of fertility problems</td>
</tr>
<tr>
<td>Info/Counc</td>
<td>Hepatitis C information and counselling issues</td>
</tr>
<tr>
<td>Infodissem</td>
<td>Wider hepatitis C information dissemination (education campaigns etc.)</td>
</tr>
<tr>
<td>Isolation</td>
<td>Experiences of feeling isolated</td>
</tr>
<tr>
<td>Jail</td>
<td>Experiences of being in jail or a partner being in jail.</td>
</tr>
<tr>
<td>Judging</td>
<td>Experiences of being judged by others</td>
</tr>
<tr>
<td>Labelling</td>
<td>Experiences of social labelling</td>
</tr>
<tr>
<td>Lifestyle</td>
<td>Changes made to lifestyle after hepatitis C diagnosis</td>
</tr>
<tr>
<td>Marginalis</td>
<td>Experiences of being socially marginalised</td>
</tr>
<tr>
<td>Medawarene</td>
<td>Medical professionals’ awareness of hepatitis C and related issues</td>
</tr>
<tr>
<td>Meddiscrim</td>
<td>Experiences of discrimination in a medical setting</td>
</tr>
<tr>
<td>Medicaltra</td>
<td>Hepatitis C transmission in a medical setting</td>
</tr>
<tr>
<td>Miscarriag</td>
<td>Experiences of miscarriage</td>
</tr>
<tr>
<td>MMT</td>
<td>Methadone maintenance treatment and other treatments experiences for drug use</td>
</tr>
<tr>
<td>Monitoring</td>
<td>Experiences of clinical testing to monitor hepatitis C</td>
</tr>
<tr>
<td>Motherhood</td>
<td>Overall issues relating to the experiences and expectations of motherhood</td>
</tr>
<tr>
<td>Nonmedawar</td>
<td>Awareness of hepatitis C among the general population</td>
</tr>
<tr>
<td>Nonmeddisc</td>
<td>Experiences of discrimination in a non-medical, social setting</td>
</tr>
<tr>
<td>Normalise</td>
<td>Normalisation of deviant behaviours and statuses within a social group.</td>
</tr>
<tr>
<td>Occupation</td>
<td>Occupation as defined by participant</td>
</tr>
<tr>
<td>Origin</td>
<td>Country of birth</td>
</tr>
<tr>
<td>Othhealth</td>
<td>Non-hepatitis C related health conditions</td>
</tr>
<tr>
<td>Parents</td>
<td>Relationship with own parents</td>
</tr>
<tr>
<td>Code word</td>
<td>Meaning</td>
</tr>
<tr>
<td>------------</td>
<td>-------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Partner</td>
<td>Relationships with current and past partners</td>
</tr>
<tr>
<td>Partnerabu</td>
<td>Experiences of having an abusive partner</td>
</tr>
<tr>
<td>PartnerHCV</td>
<td>Experiences of having a partner with hepatitis C</td>
</tr>
<tr>
<td>Partnerlw</td>
<td>Currently residing with partner</td>
</tr>
<tr>
<td>Pollution</td>
<td>Notions of being biologically and socially polluted</td>
</tr>
<tr>
<td>Prehistor</td>
<td>Pregnancy history</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>Experiences and expectations of pregnancy</td>
</tr>
<tr>
<td>Pregplan</td>
<td>Experiences and expectations of planning pregnancies</td>
</tr>
<tr>
<td>Prognosis</td>
<td>Hepatitis C prognosis in the short, medium and long term</td>
</tr>
<tr>
<td>Recsource</td>
<td>Source of participant recruitment</td>
</tr>
<tr>
<td>Rel&amp;supp</td>
<td>Relationships with and supports from family, friends, partners and children</td>
</tr>
<tr>
<td>Riskassess</td>
<td>Experiences of making risk assessments of the risk of vertical transmission of hepatitis C</td>
</tr>
<tr>
<td>Riskinfect</td>
<td>The perception and management of the risk of hepatitis C infection</td>
</tr>
<tr>
<td>Selfconcep</td>
<td>Self-concept and self-perceptions</td>
</tr>
<tr>
<td>Services</td>
<td>Health and social services relating to hepatitis C</td>
</tr>
<tr>
<td>SES</td>
<td>Socio-economic status</td>
</tr>
<tr>
<td>Sevsymptom</td>
<td>The severity of symptoms experienced</td>
</tr>
<tr>
<td>Sex work</td>
<td>Experience of sex work</td>
</tr>
<tr>
<td>Sextrans</td>
<td>Issues surrounding the sexual transmission of hepatitis C</td>
</tr>
<tr>
<td>Sickrole</td>
<td>Issues surrounding the concept of the sick role</td>
</tr>
<tr>
<td>Sourceinf</td>
<td>Source of hepatitis C infection and associated issues</td>
</tr>
<tr>
<td>Sourcepart</td>
<td>Experiences of partner being the source of hepatitis C infection through either sexual transmission or sharing injecting equipment</td>
</tr>
<tr>
<td>Sourcesupp</td>
<td>Sources of social support other than friends, family and partner</td>
</tr>
<tr>
<td>Statebenf</td>
<td>Experiences of being dependent on state benefits</td>
</tr>
<tr>
<td>Stereotype</td>
<td>Experiences and perceptions of stereotypes associated with hepatitis C and IDU</td>
</tr>
<tr>
<td>Stigma</td>
<td>Experiences of being stigmatised</td>
</tr>
<tr>
<td>Suburb</td>
<td>Suburb of residence</td>
</tr>
<tr>
<td>Suppgroup</td>
<td>Experiences of joining or contacting hepatitis C support groups</td>
</tr>
<tr>
<td>Symptoms</td>
<td>General issues relating to hepatitis C symptoms</td>
</tr>
<tr>
<td>Symptother</td>
<td>Experiences of witnessing other people experience hepatitis C symptoms</td>
</tr>
<tr>
<td>Testing</td>
<td>Experiences of being tested for hepatitis C</td>
</tr>
<tr>
<td>Testwhy</td>
<td>Reasons for hepatitis C testing and context in which testing took place</td>
</tr>
<tr>
<td>Treatment</td>
<td>Experiences and perceptions of hepatitis C specific treatment</td>
</tr>
<tr>
<td>Verttrans</td>
<td>Perceptions of the risk of vertical transmission of hepatitis C</td>
</tr>
<tr>
<td>Visibility</td>
<td>Visibility of hepatitis C</td>
</tr>
</tbody>
</table>
Appendix 12: Hierarchical coding scheme

The following bullet points display the hierarchical position of each of the codes.

**Childbearing**
- Abortion
- Birth
  - C-section
- Desfamsize
- Desirechil
- DUP
- Existchild
- Factors
- Infertil
- Miscarriag
- Preghistor
- Pregnancy
- Pregplan
- Riskassess

**Healthcare**
- Costhealth
- Docpatrel
- Dooshoppin
- MMT
- HCVhcare
  - Altthreapy
  - Diagnosis
  - Medawarne
  - Monitoring
  - Testing
    - Testwhy
  - Treatment
- Meddiscrim

**IDU**
- Drugdepend

**Info/counc**
- Infodissem

**HCVgeneral**
- Concerns
- HCVpercept
- Prognosis
- Symptother

**Motherhood**
- Badmum
- Breastfeed
- Childdiscl
- Childtest
- Custody
- Father

**Health**
- Duartinfec
- Emotionalh
- Holistique
- Lifestyle
  - Othhealth
    - HIV/AIDS
- Symptoms
  - Acutesympt
  - Anysymptom
  - Curssympto
  - Sevsymptom

**Nonmedawar**

**Recsource**
Rel&supp
- Family
- Friends
- Isolation
- Parents
- Partner
  - Partnerabu
  - PartnerHCV
  - Partnerlw
- Services
- Sourcesupp
- Suppgroup
- Suppgroup

Selfconcep

SES
- Age
- Education
- Employment
- Ethnicity
- Financial
  - Income
- Gender
- Housing
- Jail
- Marginalis
- Occupation
- Origin
- Sex work
- Statebenef
- Suburb

Sourceinf
- Hsholdtran
- Medicaltra
- Riskinfect
- Sextrans
- Sourcepart
- Verttrans

Stigma
- Auxtraits
- Blame
- Disclosure
- Discredit
- Guilt
- Judgeing
- Labelling
- Nonmeddisc
- Pollution
- Stereotype
- Visibility