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Women and Hepatitis C

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1. Introduction

Hepatitis C (HCV) is the leading notifiable blood-borne disease in Australia[1] with 12, 057 notifications in Australia for 2008, which is sixty-three percent of all blood-borne notifications[2]. Victoria recorded 2252 hepatitis C notifications in 2008[3]. HCV has been identified as a major health concern for Australian women, particularly those of child-bearing age[4]. The greatest risk for transmission of HCV is through sharing or re-using injecting equipment, and young and new injecting drug users (IDUs) have overall higher incidence of HCV infection[5]. Within this group, women are at greater risk than men[5]. Recent and ongoing research into psychological and social factors linked to HCV infection continues to find results that differ along gender lines[6,7], and which may have implications for prevention and treatment plans for women.

This paper outlines issues for women with HCV that relate to injecting drug use, prison, sexual and reproductive health, discrimination, treatment and health care services.

2. Injecting drug use

Injecting drug use (IDU) is the most common source of infection for people with HCV, with the sharing of needles, syringes and other injecting tools placing people at increased risk of contracting blood borne viruses[7]. A Sydney based study of 204 injecting drug users (IDUs) (75 women), aged below thirty years or injecting for less than six years, were found to have 'unacceptably high' incidences of HCV infection[7]. Research findings from this study of a sample of 61 HCV seroconversions indicates that women new to IDU, people from CALD (culturally and linguistically diverse) backgrounds, and those who reported mainly injecting cocaine, had significantly higher rates of incident HCV infection than others[7].

Studies suggest that women are at increased risk of HCV infection and that the 'social dynamics of sexual relationships between some IDUs appear to position women as receptive partners in the shared use of injecting equipment'[7]. Power dynamics that exist between men and women have been found to be reflected in injecting social networks and practices[1]. This extends to a lack of power in decision making to do with injecting and women's status as bottom in the hierarchy of injecting networks[1]. It is not uncommon for women to inject second, after men, thereby increasing their risk of infection[1].

Researchers have found that many women IDUs struggle financially, are homeless, and suffer from depression[1]. Women are also known to experience stigma attached to injecting drug use and HCV more than men, with feelings of shame and discrimination framing many women's stories[1].

In suggesting that resources and policy commitments be directed toward harm reduction and injecting prevention, researchers also recommend the implementation of early intervention strategies for high-risk groups including young women[5].

With increasing rates of young women being diagnosed with HCV, researchers have directed efforts towards learning more about the social and psychological aspects of young female IDUs. Based on interviews with 32 young women, the 2004 final report from the Australian Injecting & Illicit Drug Users' League (AIVL), highlights risk factors involved in HCV contraction among young women[8]. The report found that young women believed that HCV infection was an inevitable consequence of their drug use. They considered HCV a latent

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disease and therefore not an issue until much later in life. Young women reported not having access to information about safer injecting practices. Young mothers or young women who were pregnant were fearful of accessing services because of perceived discrimination, being judged as bad mothers and because they feared action that family and community services may take. Women are also more likely to share injecting equipment than men[9]. Forty-seven percent of young women said this was because their partners controlled the supply of equipment, with 50 percent reporting limited or no access to clean equipment[8].

The AIVL developed and implemented educational responses to address the areas where young women's knowledge of HCV was lacking. They also produced a national response highlighting the issues that were reported by these young women. Details of this response can be found in the Final Report[8].

3. Prisons

In the 2003 *Victorian Prisoner Health Survey*, 40 percent of prisoner participants reported having hepatitis, and 93 percent of those had HCV[10]. Overall, hepatitis was more prevalent in women (60 percent) than men (33 percent)[10]. This is consistent with other research that reports greater prevalence of HCV in women than men in prison[11,12]. Researchers have linked this to the greater proportion of women imprisoned for illicit drug related offences than men[11].

The *Queensland Women Prisoner's Health Survey*, conducted a year earlier than the Victorian research, found that 45 percent of the 212 female prisoners tested were HCV positive and 92.3 percent of those women reported a history of drug injecting[13]. The more number of years women had injected the greater likelihood they tested positive for HCV. Only 29.7 percent of women self reported HCV compared with the tested results that revealed 45 percent had the antibody. HCV was more common for repeat offenders and for those who had spent more than one year in prison. The study also found that 50.3 percent of female prisoners surveyed who had a tattoo were HCV positive, compared with 31.6 percent of female HCV positive prisoners who did not have a tattoo. Injecting drug use was significantly associated with having a tattoo. Women with more than four piercings were also more likely to be HCV positive than those with fewer piercings[13].

4. Sexual transmission

HCV is not classified as a sexually transmissible infection (STI) and research into the sexual transmission of HCV is non-conclusive, with tendencies for study findings to report low rates of transmission by sexual contact[14,15]. This is despite one study finding the presence of HCV in semen from men and in the menstrual blood of women[15]. Researchers suggest that where there is potential for blood contact between sexual partners, such as ulceration of the genital tract or during menstruation, intercourse should be avoided[14]. Others states that because of the low risk of transmission, barrier precautions during intercourse are recommended[15].

5. Contraception

In a 2003 Australian study researchers investigated the use of contraceptives by women with HCV[4]. One reason this research is important is that some forms of hormonal contraception can elevate HCV symptoms, especially for women who have severe symptoms or elevated liver enzyme levels[4].

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A self-administered questionnaire was completed by 462 women recruited from agencies providing services to women with HCV in Victoria and the ACT[4]. Results suggest that women with HCV have lower levels of contraceptive use than women without the virus. One of the concerns is that women who become pregnant won't be able to take the usual HCV treatment, which is associated with birth defects. Researchers claim the topic of contraception and HCV warrants further investigation.

The researchers named additional areas of focus, including the categorisation of relationship and the impact of this on women's responses, such as those who identified as lesbian. Although lesbian and samesex attracted (SSA) women were found to be less likely to use contraception, some SSA identifying women were also having sex with men[4]. This study also drew attention to women's reluctance to use mainstream health service providers, including family planning services, because of stigma attached to HCV[4].

6. Pregnancy

Sixty percent of women with HCV in the 2003 study discussed in the last section reported receiving no information about HCV and pregnancy from their health service providers[4]. This is consistent with other Australian research that found only 20 percent of obstetricians always ask pregnant women about risk factors related to exposure to blood-borne viruses[16]. This is important because treatment options can impact on pregnancy. Antiviral drugs used for treatment of HCV include pegylated interferon and ribavirin. Women on treatment are advised that they and their partner should each use a form of contraception so as to ensure that pregnancy does not occur[17]. This should continue for six months after the treatment also. The reason is that both drugs, but particularly ribavirin can cause birth defects[17].

6.1 Antenatal factors

Research into incidences of transmission from women with HCV to their babies (vertical transmission) is not conclusive. There is no evidence to determine the relationship between delivery mode and transmission of HCV, so that preference of vaginal or caesarean delivery for women need not be made on the basis of their HCV status[15]. An approximate rate of HCV transmission during pregnancy and childbirth is 5 percent[18]. That risk increases when women are also infected with human immunodeficiency virus (HIV)[18].

All babies born to women with HCV will have HCV antibodies, but this does not mean the infant has contracted the disease or that the baby is immune to it[18].

6.2 Breastfeeding

There is no conclusive evidence for transmission of HCV during breastfeeding[14] and Hepatitis Australia states that there are no confirmed reports of HCV transmission from women to baby by breast milk[18]. HCV has been found in breast milk but the levels have not been considered a transmission risk[19]. The *Hepatitis C Resource Manual* encourages women with HCV to breastfeed because the 'health benefits of breastfeeding' outweigh the 'low risk' of HCV transmission[19]. However, researchers recommend that breastfeeding cease if nipples are cracked or bleeding. In this instance where there is a chance of blood entering the milk, women are advised to express the milk and discard it until the lesions are healed[17-19].

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Despite research suggesting low risk of HCV transmission through breastfeeding, a substantial proportion of obstetricians have been found to give incorrect advice about HCV transmission and breastfeeding[16].

7. Alcohol

Hepatitis Australia provides a range of recommendations regarding alcohol consumption and HCV[18]. While stating that there is no evidence to suggest alcohol abstinence is necessary, unless there is cirrhosis of the liver, they do recommend alcohol reduction as it does increase liver damage[18]. Research indicates that an alcohol intake of more than 4 standard drinks a day has a deleterious effect on the progression of HCV[20], and that while women with HCV are reported to live longer than men with the virus, heavy drinking in women eliminates that advantage[21]. A recent US study found that women with HCV who were not heavy drinkers died at an average age of 61 years, where women with HCV who were heavy drinkers died on average at 49 years[21]. This is a difference of twelve years. For men that difference was only five years[21].

8. Tobacco

Hepatitis Australia states that women with HCV who smoke tobacco should stop as research shows that it can exacerbate liver disease[18]. Smoking also increases the risk of heart disease, and women who smoke are found to experience menopause five years earlier than those who do not[18].

9. Employment

Women living with HCV have identified participation in the workforce as important to restoring their sense of self-worth, being involved in community and in assisting them to manage the day-to-day effects of their illness[22].

A 2003 study revealed that employers expected honesty from their employees, but that disclosure of a woman's HCV status may influence their decision to hire her[22]. The same study interviewed Australian women living with HCV who reported that stigma attached to the virus, and the impact of this on employer and fellow employee attitudes, was a barrier for women obtaining and staying in paid employment[22]. When faced with health concerns that may include fatigue, lethargy and nausea, disclosure to employers was stated as an issue. For women in this study, disclosure generally resulted in a strained work environment where discriminatory events were common and subsequent discomfort and fear was experienced[22]. The research revealed that misconceptions about HCV drove employer attitudes and reinforced the stigma attached to and experienced by women living with HCV[22].

10. Sexual identification

Same-sex attracted women are over represented among women with HCV[23]. A 2005 Australian study of women living with HCV found that of the 462 respondents 23 percent (106) identified as lesbian or bisexual. While lesbian and heterosexual women were more likely to be currently seeing a doctor than bisexual women, bisexual and lesbian women were more likely to report having changed doctors in the past 12 months because of the GP's attitude. Lesbians and heterosexual women were found to access health services more than bisexual women. In concluding, the researchers argued that it is important to recognise the specific health needs of bisexual and lesbian women[23].

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11. Treatment and medical care

Researchers state that treatment uptake for HCV has always been low in Australia[24]. Women have been found to be less likely to seek medical treatment for HCV than men[25]. In one Australian study, those participants who had elected not to have treatment stated that their reasons had to do with side effects and a belief in poor success rate of treatment. They also relayed concern that treatment would impact on work, family or friends[24].

Another Australian study that focussed on women's stories about living with HCV found that women wanted access to women specific HCV services where they would be able to have their sexual and reproductive health concerns addressed[1]. The study raised the issue of gaps in medical and epidemiological knowledge about HCV and that uncertainties arising from these gaps hampered women's decisions[1]. Women stated that HCV should be incorporated into women's health services as a key issue[1]. They also said that wider social issues associated with HCV, including poverty, homelessness, disconnection from family and friends, addiction or IDU lifestyle and mental illness all needed to be considered by health services[1].

Women living with HCV have also reported the need for non-judgemental care from primary health care providers[1]. This is in light of findings that suggest a general sense of prejudice and lack of knowledge about HCV amongst health professionals[26]. One study reported that fifty-four percent of health professionals believed people with HCV died prematurely; 55 percent did not know that a pharmaceutical treatment was available; 25 percent were unaware that presence of hepatitis C antibody does not indicate current infection, and 50 percent of nurses and 45 percent or pharmacists incorrectly thought that HCV is most commonly spread through sexual contact[26]. Dentists reported treating people with HCV differently, with 30 percent stating that they should be the last person seen on any day. This is consistent with earlier research that found some dentists changed their practice when aware of working with an HCV client[27]. Complementary therapists, medical practitioners and nurses reported that their willingness to treat people with HCV 'was influenced by their attitudes towards injecting drug users', rather than their knowledge about HCV[26]. This highlighted the role of social prejudice in service provision and is a concern given the broad range of social, physical and mental health needs that women with HCV have[28].

12. Conclusion

Research demonstrates that living with HCV is a gendered health issue. This paper has highlighted a number of these issues, including the influence of power relations and gendered social practices between men and women on the incidence of HCV infection in young women, particularly those who are injecting drug users. The lack of knowledge in young women around safe injecting practices has also been reported. The greater number of female prisoners over male prisoners with HCV has been highlighted, and correlations between women in prison, injecting drugs, women having a tattoo or piercing and HCV were found.

Contraception was deemed an important issue for women with HCV for a range of reasons including treatment management, with pregnant women unable to use antiviral drugs. Alcohol was reported to have a negative effect on life expectancy for women with HCV and smoking tobacco was seen to cause increased liver damage. Employment was indicated to be a life enhancing factor for HCV positive women, but discrimination and the stigma

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attached to HCV was a barrier for many women, preventing them from accessing or remaining in paid work.

Sexual identity influenced the treatment behaviours of women with HCV and was also found to be a factor in healthcare providers' responses, with same-sex attracted women being treated differently to heterosexual women with HCV. Health professionals' overall knowledge about HCV was found to have significant gaps, and was influenced by their attitudes towards injecting drug use. Women with HCV reported the need for women specific health care services and greater access to sexual and reproductive health care.

The issues highlighted in this paper for women with HCV reveal the need for a gendered approach to all aspects of healthcare, information provision, prevention strategies, education, policy and research related to HCV.

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