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Women & Hepatitis C

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Introduction

There are approximately 220 000 people in Australia living with chronic hepatitis C virus (HCV)¹ and about one third of those are women². The blood borne virus has been identified as a major health concern for Australian women, with reports that for the first time, in 2001, the number of new HCV notifications among women aged 15-19 were higher than those for men of the same age³. The greatest likelihood of HCV infection for anyone is through injecting drug use, and young and new injecting drug users (IDUs) have overall higher incidence of HCV infection⁴. Within this group, women are at greater risk than men⁴. HCV is likely to affect women differently to men, physically, economically and personally⁵. Recent and ongoing research into psychological and social factors linked to HCV infection continues to find results that differ along gender lines, and which may have implications for prevention and treatment plans for women.

Issues

1. *Injecting Drug Use and HCV*

Illicit drug injection 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 viruses⁶. A Sydney based study of 204 injecting drug users (IDUs) (75 women), aged below thirty or injecting for less than six years, were found to have 'unacceptably high' incidences of HCV infection. Research findings from this study indicate that new female IDUs, 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 in the sample of 61 HCV seroconversions.

Women are often initiated into drug use by men in their lives, who in turn control women's drug using behaviour⁷. This means that women may inject second, after men, using the same equipment or that they are injected by men⁷. There are multiple ways infection can occur during injecting, including: blood in the syringe, in the filter equipment, on the tourniquet or on another person's finger when they apply pressure to the injection site⁷. Women injecting second would therefore be at greater risk of infection or re-infection.

Researchers have also found that compared to women who never, or no longer injected, women currently injecting are more likely to live below the poverty line, less likely to contact

¹ Harris, M. & Richters, J. (2006) *Psychosocial aspects of living with hepatitis C*. Social Research Briefs 8. National Centre in HIV Social Research. University of New South Wales. Located at <http://nchr.arts.unsw.edu.au/pdf%20reports/SRB08.pdf> Accessed 23 April 2007.

² Gifford, S., O'Brien, M. Smith, A., Temple-Smith, M., Stooze, M., Mitchell, M. & Jolley, D. (2005). Australian women's experiences of living with hepatitis C virus: Results from a cross-sectional study. *Journal of Gastroenterology and Hepatology*, 18: 841-850. Social Research Briefs 8/004. National Centre in HIV Social Research. University of New South Wales. Located at <http://nchr.arts.unsw.edu.au/pdf%20reports/SRB08.pdf> Accessed 23 April 2007.

³ Banwell, C., Gifford, S. & O'Brien, M. (2003) Disturbingly low levels of contraception among women living with hepatitis C. *Australian and New Zealand Journal of Public Health* 27(6):620-626.

⁴ Maher, L., Li, J., Jalaludin, B., Chant, K. & Kaldor, J. (2007) High hepatitis C incidence in new injecting drug users: A policy failure? *Australia and New Zealand Journal of Public Health* 31(1):30-35.

⁵ Gifford, S. & O'Brien, M. (2001) Bad blood, bad livers, bad women? Women's experiences of living with hepatitis C. *Australian Hepatitis Chronicle*, 8: 9-13.

⁶ Hocking, J. Crofts, N., Aitken, C. & MacDonald, M. (2001) Epidemiology of the hepatitis C virus among injecting drug users, In Crofts, N., Dore, G. & Locarnini, S. (Eds.) *Hepatitis C: An Australian perspective*. Melbourne: IP Communications: 260-295.

⁷ Australian Hepatitis Council; Australian National Council on AIDS Hepatitis C and Related Diseases (ANCAHRD) (2006) *Women and hepatitis C: A resource for women with hepatitis C*. Located at <http://www.hepatitisaustralia.com/PDFs/Women%20and%20Hep%20C%20October%202006.pdf> Accessed 23 April 2007.

an HCV support service and are more likely to have been treated negatively by health professionals such as dentists, pharmacists and nurses⁸.

Women are also found to experience stigma attached to injecting drug use and HCV more than men who tend to downplay the physical and social impact of the infection^{1,5}.

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.

2. *Injecting Drug Use, Age and HCV*

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 women⁹. The report found that young women believed that HCV infection was an inevitable consequence of their drug use. They considered HCV a latent disease and therefore an issue for older women. 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. Forty-seven percent (47%) of young women said that their partners controlled the supply of equipment and 50% reported limited or no access to clean equipment, and had a lack of knowledge about cleaning used injecting equipment⁹.

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 Report⁹.

3. *Prisons and HCV*

A 2001 study of prisons in Western Australia found that 58% of women tested in Perth's women's prison were positive for HCV. This was compared to around 35% of men tested in Perth's two male prisons¹⁰. In the *Queensland Women Prisoner's Health Survey*, 45% of female prisoner participants tested HCV positive¹¹. In the 2003 *Victorian Prisoner Health Survey*, 40% of prisoner participants identified having hepatitis¹². When asked to specify the stream of hepatitis, 93% of prisoners identified hepatitis C, 39% indicated hepatitis A and 65% reported hepatitis B. Overall, hepatitis was more prevalent in women (60%) than men (33%)¹².

⁸ Gifford, S. (2001) Women living with hepatitis C: A summary of findings from a recent report. *Good Liver* Spring, 4-5.

⁹ *Going second? Young Women Injecting Drug Users project* (2004). Australian Injecting & Illicit Drug Users' League. Located at <http://www.aivl.org.au/files/YoungWomen.InjectingDrugUsers.Project.pdf> Accessed 23 April 2007.

¹⁰ Hepatitis C: A study of prevalence in WA prisons (2001) WA Hepatitis Council & Department of Justice in Western Australia, In Hellard, M. Crofts, N & Hocking, J. (2002). Hepatitis C among inmates in Victorian correctional facilities: A report of the prevalence of hepatitis C virus and the risk behaviours associated with the transmission of hepatitis C virus in Victorian correctional facilities. Burnet Institute: Melbourne, Vic.

¹¹ Hockings, B., Young, M., Falconer, A. & O'Rourke, P. (2002) Queensland Women Prisoners' Health Survey. Department of Corrective Services: Brisbane.

¹² *Victorian Prisoner Health Survey* (2003) Department of Justice, Government of Victoria. Located at: http://www.justice.vic.gov.au/wps/wcm/connect/DOJ+Internet/resources/file/eb1c92417c30a58/Victorian_Prisoner_Health_Study_February_2003_Part1.pdf Accessed 14 May 2007.

4. Prisons, Injecting Drug Use and HCV

A 2001 study that randomly sampled injecting drug users from all New South Wales correctional centres found that female IDUs had a 90% HCV prevalence, while the prevalence for male IDUs was 66%. The *Queensland Women Prisoner's Health Survey* found that 45% of female prisoners tested were HCV positive and 92.3% of those women reported a history of drug injection¹². In an earlier Victorian study, 630 prisoners from five correctional facilities were tested for HCV¹³. Three hundred and sixty-two (57.5%) tested positive for HCV antibody. Fifty-five percent of males and 66.7% of females tested HCV antibody positive. Three hundred and thirty-seven prisoners (93.9%) in the HCV positive group reported a history of injecting drug use. Participants reported that they were more likely to share a needle in prison and less likely to use a clean syringe. There was no significant association between sharing needles and being HCV positive, but there was between sharing spoons¹³. Researchers from this study state that prisons alter the behaviour of IDUs who are less likely to inject safely because they do not have access to clean injecting equipment¹³.

5. Prisons, Tattooing and HCV

Some HCV resources state that there is no increased risk of contracting HCV through ear piercing or tattooing¹⁴, but that people should be alert to the presence of unclean piercing and tattooing equipment^{14,15}. However, there are studies that do associate tattooing with HCV prevalence, particularly within the prison setting. One Victorian study found that prisoners who tested positive for HCV were more likely to have had a tattoo in prison¹³. They also found that risk factors for HCV infection among inmates who had never injected drugs were having a tattoo in prison and being of Aboriginal and Torres Strait Island (ATSI) descent¹³. A Queensland study found that 50.3% of female prisoners surveyed who had a tattoo were HCV positive¹¹. This was compared with 31.6% 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. The researchers concluded that women prisoners in this study with a tattoo were more likely to have HCV¹¹.

6. Sexual Transmission and HCV

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^{16,17}. However, blood-to-blood contact during intercourse and other sexual practices will increase the chance of HCV infection where one or more persons have HCV. These sexual practices may include the use of sex toys, 'rough sex' or practices that involve ripping or tearing around the genital or anus area¹⁷. Women with HCV or with a partner who has HCV are advised to avoid intercourse or genital sexual practices if

¹³ Hellard, M. Crofts, N & Hocking, J. (2002). *Hepatitis C among inmates in Victorian correctional facilities: A report of the prevalence of hepatitis C virus and the risk behaviours associated with the transmission of hepatitis C virus in Victorian correctional facilities*. Burnet Institute: Melbourne, Vic.

¹⁴ Berkman, A. & Bakalar, N. (2001) *Hepatitis A to G: The facts you need to know about all the forms of this dangerous disease*. New York: Warner Books.

¹⁵ *National Hepatitis C Resource Manual* (2001) Australian Institute for Primary Care, La Trobe University.

¹⁶ Harley, H., Shaw, D. & Steven, I. (2003) Hepatitis C: Ongoing management of hepatitis C. *Australian Family Physician*, 32 (10): 820-825.

¹⁷ MacDonald, M., & Wodak, A. (2003) Preventing transmission of hepatitis C. *Australian Family Physician*, 32 (10):799-804.

there is ulceration around their genital area and during menstruation, with studies finding the presence of HCV in semen from men and in the menstrual blood of women^{16,17}.

7. Contraception and HCV

A 2003 Australian study by Banwell and colleagues, investigated the use of contraceptives by women with HCV. 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.

A self-administered questionnaire was completed by 462 women recruited from agencies providing services to women with HCV in Victoria and the ACT. Results suggest that women with HCV have lower levels of contraceptive use than women without the virus and despite the low risk of sexual transmission of HCV, Banwell and colleagues claim that for this reason alone, the topic of contraception warrants further research. 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 identify as lesbian. Although lesbian and same-sex attracted women are less likely to require pregnancy related contraception, transmission may occur during sexual activity where blood-to-blood contact occurs, and contraceptive protection is recommended. Banwell's study also drew attention to women's reluctance to use mainstream health service providers, including family planning services, because of stigma attached to HCV.

8. Pregnancy and HCV

Antiviral drugs used for treatment of HCV include interferon and ribavirin, although ribavirin is not effective on HCV by itself. When interferon is administered by itself 15-25% of people with HCV show decreases of the enzyme alanine aminotransferase (ALT) in their blood¹⁴. ALT and aspartate aminotransferase (AST) are enzymes present in the liver; they leak into the bloodstream when liver cells are damaged¹⁴. A blood reading of ALT and AST levels is one test administered to diagnose HCV and is also used to monitor liver function. When interferon is taken with ribavirin the cure rate for people with HCV is around 40%¹⁴. However, interferon should not be taken by pregnant women^{18,19} due to the unknown effects it has on pregnancy and breastfeeding, and women already treated with interferon and ribavirin are recommended to avoid pregnancy during treatment and six months post-treatment¹⁸. Furthermore, ribavirin can interfere with the development of a foetus, causing birth defects^{3,19}.

9. Antenatal Factors and HCV

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 status¹⁷. An approximate rate of HCV transmission, either in utero, during childbirth or through breastfeeding, is around 5%, with an estimated 75 children born with HCV infection each year in Australia²⁰. When other medical

¹⁸ Harley, H., Shaw, D. & Steven, I. (2003) Hepatitis C: Ongoing management of hepatitis C. *Australian Family Physician*, 32 (10): 820-825.

¹⁹ Giles, M., Sasadeusz, J., Garland, S., Grover, S. & Hellard, M. (2004) An audit of obstetricians' management of women potentially infected with blood-borne viruses. *Medical Journal of Australia* April 180: 328-332.

²⁰ Dore, G., McDonald, M., Law, M. & Kaldor, M. (2003) Epidemiology of hepatitis C virus infection in Australia. *Australian Family Physician*, 32 (10): 796-798.

factors, such as HIV are added¹⁷, that figure can reach as high as 36%. Additional factors that may increase the risk of HCV transmission from mother to baby include the woman being in the early phase of HCV infection, if she has serious liver damage or if she has high levels of the virus in her blood²¹.

All babies born to women with HCV will have HCV antibodies, but in 92-95% of babies, by the age of eighteen months they will test negative for the virus, with no sign of HCV antibody²¹.

One study revealed that 9% (n=174) of pregnant women living with HCV had been advised to have a termination because of their HCV status⁸.

10. Breastfeeding and HCV

There is no conclusive evidence for transmission of HCV during breastfeeding¹⁸. The *National Hepatitis C Resource Manual* encourages women with HCV to breastfeed because the 'health benefits of breastfeeding' outweigh the 'low risk' of HCV transmission¹⁵. However, researchers recommend that breastfeeding cease if nipples are cracked or bleeding^{15,17-19}. Despite a general acceptance that no direct association between breastfeeding and transmission of HCV can be found, research into obstetricians' work with women around blood-borne viruses found that a substantial proportion of obstetricians were giving incorrect advice about HCV transmission and breastfeeding¹⁹.

11. Alcohol and HCV

Research indicates that an alcohol intake of more than 4 standard drinks a day has a deleterious effect on the progression of HCV,²² and while women with HCV are reported to live longer than men with the virus, heavy drinking in women eliminates that advantage²³. A recent US study found that women with HCV who were not heavy drinkers died at an average age of 61, where women with HCV who were heavy drinkers died on average at age 49²³.

12. Employment and HCV

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 illness²⁴. Researchers have found that women living with HCV generally live below the poverty line and find it difficult to meet the costs of regular expenses, ranging from food, rent, clothing, utilities and transport⁸. Employment then, is an important factor in the economic, social and emotional well-being of women with HCV.

Gaining and maintaining employment has been cited as difficult by women with HCV⁵ and research into employer attitudes on hiring women with HCV highlights this. 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 her²⁴. 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

²¹ *National Hepatitis C Resource Manual* (2001) Australian Institute for Primary Care, La Trobe University.

²² Batey, R. (2003) Chronic hepatitis C. *Australian Family Physician*, 32 (10):807-811

²³ Good Liver: Newsletter of the Hepatitis C Council of Victoria. *Heavy drinking reduces lifespan advantage of women over men with hepatitis C*. Melbourne, (Vic) Autumn 2007:2.

²⁴ Platt, M. & Gifford, S. (2003) Promoting health through promoting work: The dilemmas of disclosure in the workplace for employers and for Australian women living with hepatitis C. *Health Promotion Journal of Australia*, 14(3): 180-186.

and staying in paid employment²⁴. 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.

The research revealed that misconceptions about HCV drove employer attitudes and reinforced the stigma attached to and experienced by women living with HCV.

13. Treatment, Medical Care and HCV

Women living with HCV generally have better treatment responses than men²⁵. However, less than 5% of HCV infected people seek clinical treatment and less still complete treatment once started²⁶. A 2004 study into the psychological and social factors that influence people with HCV around accessing treatment, found that 52% of participants (n=215) had never been treated for HCV and that women were more significantly likely never to have received treatment than men²⁵.

Researchers in a 1999 study interviewed 25 women living with HCV and found that women reported receiving different medical care than men with HCV⁵. Men's HCV health issues were reportedly treated as HCV related while women's HCV health issues were said to be linked to their gender. One woman stated that the doctor asked her about her menstrual cycle when the woman had raised what she knew to be an HCV related issue. Other women in the study reported that all their HCV related health problems were dismissed as 'women's reproductive health problems'.

14. Sexual Identification and HCV

A 2005 study looking at lesbian and bisexual women's health and social experiences of living with HCV found that same-sex attracted women were over represented among women with HCV²⁷. Of 462 women who completed a self-administered survey, 23% (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. Forty-five percent (45%) of lesbian and bisexual women reported having their HCV status disclosed without their permission by friends, family and at work. 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 women²⁷.

Conclusion

Women accounted for 35% of the total HCV notifications made in Australia between 1991 and 2005²⁸. Numbers of young women with HCV either remain equal to or higher than those

²⁵ McNally, S. & Temple-Smith, M. (2004) Psychological and social factors associated with uptake and maintenance of clinical treatment for hepatitis C. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne. Located at http://www.health.vic.gov.au/researchprograms/downloads/hepc_dhs_02to03.pdf Accessed 16 April 2007.

²⁶ Pitts, M., O'Brien, M. & McNally, S. (2007) Psychological and social factors associated with uptake and maintenance of clinical treatment for hepatitis C (Now later or never: Challenges of hepatitis C treatment). Health Sciences, La Trobe University, Australian Research Centre in Sex, Health and Society. Located at <http://www.latrobe.edu.au/archshs/hepatitis.html> Accessed 18 April 2007.

²⁷ Banwell, C., Bammer, G., Gifford, S. & O'Brien, M. (2005) Australian lesbian and bisexual women's health and social experiences of living with hepatitis C. *Health Care for Women International*, 26(4): 340-354.

²⁸ Hehr, R. (2007) Statistically speaking: hepatitis C in Australia. *Country Matters* Autumn: 4.

for young males with HCV. However, as a minority group catered for within HCV related healthcare services, women report receiving inappropriate care. This is despite findings that women with HCV have poorer mental and physical health than the general population²⁹. In this and many other ways, research demonstrates that living with HCV is a gendered health issue. This review 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. Employment was indicated to be a life enhancing factor for HCV positive women, but discrimination and the stigma attached to HCV was a barrier for many women, preventing them from accessing or remaining in paid work.

Women reported being treated differently to men by health professionals and one study found that women were less likely to seek treatment than men. 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.

The issues highlighted in this review 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.

²⁹ Gifford, S., O'Brien, M., Banner, G., Banwell, C. & Stooove, M. (2003). Australian women's experiences of living with hepatitis C virus: Results from a cross-sectional study. *Journal of Gastroenterology and Hepatology*, 18: 841-850. Social Research Briefs 8/004. National Centre in HIV Social Research. University of New South Wales. Located at <http://nchr.arts.unsw.edu.au/pdf%20reports/SRB08.pdf> Accessed 23 April 2007.