



# Women and HIV: the impacts of stigma and discrimination

By Rachel Lennon and Dawn Wilcock

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By the end of 2007, 2,025 women living in Australia had been diagnosed HIV-positive. Of this figure, 527 women had died.<sup>1</sup> Contrary to misconceptions commonly associated with HIV and women, the majority of infections are attributed to sexual encounters with male partners and not through sharing needles or sex work. This article looks at some of the issues faced by HIV-positive women in experiencing stigma and discrimination.

## Heterosexual transmissions

Concurrent with existing data in Australia, the United Nations and World Health Organization (WHO), report a global trend for sustained increase in the transmission of HIV through heterosexual contact.<sup>2</sup> Potentially, these trends are a predictor for rises in infections amongst Australian women, requiring a deeper knowledge of the social differences between positive women and positive men. The issues faced by HIV-positive women include considerations of childrearing, menopause and other complex physical changes they face throughout their lifetimes. This does not take into account the psychological issues faced in disclosing their status to their families, and/or telling their children that they too are HIV-positive through parent to child transmission.<sup>3</sup> Additionally, there is a lack of research about the effects of ageing, physical changes and

reactions with HIV medication.<sup>4,5</sup> However compelling these issues may appear, HIV-positive women remain a minority within a minority.

## Trends in Australia

Heterosexual transmission in Australia is on the rise. According to the National Centre in HIV Epidemiology and Clinical Research (NCHECR) *Surveillance Report* (2007), there has been an increase of 35 percent in HIV heterosexual infections between 2005 and 2006 across all Australian states. Western Australia data shows that in 2005, heterosexual transmissions represented 50 percent of all new infections in the state. This compares to 39 percent for the average of the previous five years. In Victoria, surveillance data has shown that heterosexual notifications have doubled in the past 24 months.<sup>6</sup>

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*'Women living with HIV/AIDS struggle to be seen and heard within the current HIV community. This struggle feeds their existing sense of isolation. In addition to their struggle to be acknowledged and be embraced within the HIV community, they fear disclosure, particularly to the wider community.'* (Jayne Russell, Researcher, ARCSHS)

HIV amongst women is perceived as an infection that is contracted through 'bad behaviour' such as sex work or injecting drug use. Research shows that rigorous screening for STIs and extensive education about the impacts of unprotected sex has in fact resulted in low incidence of STIs amongst licensed brothel workers.<sup>7</sup> Needle exchange programs and education around injecting drug use have also resulted in low incidence of HIV in the injecting drug community. For Victorian women living with HIV, heterosexual relations with long-term male partners have been the predominant mode of transmission.<sup>8</sup>

### Impacts of stigma and discrimination

*'I take seven pills daily that make me sick to my stomach. I experience nausea, diarrhoea, vomiting and the worst of all, mood swings. But yet it is still not the worst part of having HIV. It is the stigma.'* (A Positive Woman)<sup>11</sup>

HIV-positive women in Australia experience greater levels of stigma and discrimination, have less support to draw upon<sup>12</sup> and, until diagnosis, many positive women never thought they were at risk of HIV infection. The shock of diagnosis can result in delaying commencement of treatment which may affect a positive woman's health if it is needed right away. A positive diagnosis may have difficult implications for the relationship with the person who infected them, particularly if children are involved. This may lead to negotiations around the future of the relationship at the same time as understanding the ramifications of being HIV-positive: an incredibly difficult time.

### Positive Women

**Positive Women (Victoria) seeks to provide support and advocacy for these women, and to raise the profile of HIV and women in the community.**

In the early years of the HIV epidemic, public conceptions of women with HIV focused on childbearing and saw women as the main carriers of HIV who passed the fatal infection on to her family.<sup>9</sup> Even though HIV has a higher profile in the community, there is still a lack of research and action addressing the physiological, sociological and emotional impacts of HIV on women.<sup>10</sup> There is also a notable gap around advocacy for positive women. Taking into account the diversity amongst women with HIV, the impact of HIV on women needs further exploration alongside social determinants, effective prevention strategies and more robust support models.

Positive Women (Victoria) aims to build an evidence base substantial enough to bring about sustainable lasting change either on a policy level or in the consciousness of the public.

In Australia, sexual health is largely seen as the responsibility of the woman while a man's sexual practices (safe or unsafe) are expected to be accepted by the woman.<sup>13</sup> Additionally, it is suggested that heterosexual men tend to discourage condom use in sexual relationships and have more sexual partners.<sup>14</sup> The incidence of violence against women is higher when they ask their partner to use a condom or when their partners discover they have attended HIV testing and counselling.<sup>15,16</sup> This type of behaviour is unacceptable, as men need to be equally responsible for safe-sex practices.<sup>17</sup>

Stigma and discrimination have both physical and psychological impacts on people living with HIV/AIDS.<sup>18</sup> Negative social responses have been shown to affect the levels of uptake in antiretroviral medication and some services for people living with HIV. Out of fear of stigma and discrimination, some positive people are less likely to: participate in HIV services such as education programs around preventing mother-to-child transmission in pregnancy; receive treatment information/counselling; or participate in other programs aimed at building better levels of social inclusion.<sup>19,20</sup>

The impact of discrimination on HIV-positive women's mental health includes high rates of depression and trauma resulting in disease progression by decreasing CD4 lymphocytes and increasing viral load.<sup>21</sup> Unfortunately, depression is one of the most common mental illnesses amongst people living

with HIV with higher rates occurring among women.<sup>22</sup> One study examining the effects of depressive symptoms and mental health on highly active antiretroviral therapy (HAART) uptake amongst HIV-positive women found that poor mental health and depressive symptoms significantly reduced the probability of using HAART.<sup>23,24</sup> Thus, strong support networks are crucial and the level of support a woman can expect from her family and friends is indicative of when and how she discloses to them. Parents usually respond with shock and can communicate this in a number of different ways, both supportive and destructive. It has also been revealed that women will 'put off' treatment as they find it distressing to their mental health.<sup>25</sup>

### Positive parenting

In Australia in 2002, 50.2 percent of women infected with HIV/AIDS had dependent children<sup>26</sup>, and the number of HIV-positive women having children has increased since then. Research has shown that stigma towards positive women is a minor factor in non-disclosure to children; a larger one is the fear that their children will experience stigma.<sup>27</sup> Parents of children's friends are not always aware of the low level of transmission risk involved in HIV and can put barriers in the way for their children in socialising with children of HIV-positive mothers.

Challenges faced by positive women when disclosing their status to children include fear of rejection, inability to control secondhand

disclosure by their children, an increase in vulnerability for the child and the child's ability to cope with such information.<sup>28</sup> Meanwhile, the majority of women living with HIV are infected by male partners who may have acquired HIV from having sex with another person (male or female), or intravenous drug users. Therefore, providing explanations that are appropriate for children can be very difficult.<sup>29</sup> Women who become pregnant while positive seem to be able to disclose more freely than women who already have children when diagnosed.

### Addressing the issues

In Australia, a great deal of communication about HIV has been predominantly in the gay community. Most gay clubs and bars have accessible information about HIV; gay dating websites have information about keeping safe from HIV. Women are disadvantaged by a lack of timely and accessible information about HIV. Since the campaigns of the late 1980s featuring the Grim Reaper, no other major campaigns about HIV/AIDS have been focused on women. The campaigns available to the public had adopted shock tactics in relation to HIV/AIDS rather than the use of educational means to facilitate public behavioral changes in sexual practice. Regardless of the blame women receive for transmitting the virus, there have been no gender specific campaigns.<sup>30</sup>

It is clear that stigma and discrimination are major hindrances to accessing medication for HIV-positive women. Stigma also negatively impacts upon mental health, increases violence and ultimately, has led to further transmission of HIV and disease progression. With infections in women on the rise, it is time to develop methodology to address diversity and poverty, and turn it into a substantial campaign. We have seen several women-specific programs and strategies assist in preventing HIV transmission and HIV disease progression such as peer support programs, counseling, and education programs to name a few. Many of

these have been implemented by organisations such as Positive Women Victoria. But we need to see more.

For further information about HIV and women, the table below provides service contacts.

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**Rachel Lennon is a former Health Promotion Coordinator for Positive Women Victoria and Dawn Wilcock is a former Director of Positive Women Victoria.**

### Organisations to contact

#### Positive Women Victoria

[www.positivewomen.org.au](http://www.positivewomen.org.au)

T: 03 9076 6918

#### Straight Arrows

[www.straightarrows.org.au](http://www.straightarrows.org.au)

T: 03 9076 3792

#### PEP (Post-Exposure Prophylaxis)

T: 1800 889 887 (24 hours)

#### Positive Counselling

[www.positivecounselling.org.au](http://www.positivecounselling.org.au)

T: 03 9530 2311

#### PLWHA Victoria (People Living With HIV/AIDS)

[www.plwhavictoria.org.au](http://www.plwhavictoria.org.au)

T: 03 9865 6772