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HIV Futures II: People with Haemophilia

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Introduction

The HIV Futures Study is the largest of its kind in Australia. It is designed to provide HIV, health and funding agencies, as well as the affected community, with a picture of the overall situation of people living with HIV/AIDS (PLWHA) in Australia.

The *HIV Futures II* survey was conducted by the Living with HIV research program at the Australian Research Centre in Sex, Health and Society, La Trobe University, in the second half of 1999. The survey asked PLWHA about their health, use of antiretroviral and complementary treatments, use of information and support services, and their housing and financial situation. It also asked about sex and relationships, people's social supports, recreational drug use, work situation and future planning.

HIV Futures II is the second time this national survey has been conducted. The research team held consultations with PLWHA and HIV organisations around the country in order to improve this follow-up survey.

The survey was completed by 924 PLWHA from all States and Territories in Australia who represent over 8% of the current population of PLWHA in Australia, as estimated by the National Centre in HIV Epidemiology and Clinical Research (NCHECR; 1999).

The results of this study have been reported in the document *HIV Futures II: The Health and Well-Being of People with HIV/AIDS in Australia*. The HIV Futures Community Report contains a vast amount of information about the social impacts of HIV/AIDS including: treatment uptake and health management; the impact of HIV/AIDS on sexual practice; the involvement of respondents in community organisations, and the importance of HIV/AIDS organisations to PLWHA; the impact of HIV/AIDS on work and employment participation; and the financial impact of living with HIV/AIDS. This report relates specifically to people with Haemophilia.

Of the total sample of PLWHA the majority (90.0%) of respondents were male, 9.7% were female, and 0.3% were transgendered people. Respondents' ages ranged from 18 to 75 years (median = 41.0 years, mean = 42.1 years). Respondents' ages at the time of diagnosis with HIV ranged from 9 to 69 years (median = 32.0 years, mean = 33.2 years).

Of the 924 PLWHA, 77.6% said they are homosexual, 15.5% are heterosexual, 6.2% are bisexual, and 0.6% did not indicate their sexual orientation. Both men and women are represented in each of these categories. Data were weighted so that sample demographics matched those of the *Australian HIV Surveillance Report* [NCHECR, 1999] according to gender, State of residence, mode of infection, and diagnosis of an AIDS-defining illness.

Demographics

Of the 924 PLWHA who completed the survey, 32 were people with Haemophilia which represents 18.1% of the people with Haemophilia and HIV in Australia. The ages of people with Haemophilia ranged from 24 to 73, with an average of 40.7 years. This was not significantly different to the remainder of the sample. Respondents' ages at the time of testing HIV seropositive ranged from 9 to 58, with an average of 30.2 years.

According to exposure category data contained in the Australian HIV Surveillance Report (NCHECR, 1999), 1.7% of the total number of adult HIV infection are attributed to Haemophilia/coagulation disorder. In the *HIV Futures II* sample, 3.5% of respondents reported this exposure category.

Of the 32 people with Haemophilia, 12 received their copy of the survey from the Haemophilia Foundation, 14 received theirs from a PLWHA organisation or a health centre and four were on the mailing list for the survey from the first HIV Futures Survey. Of the 32 people with Haemophilia who completed the survey, 19 are from Victoria, 3 from Queensland, 8 from New South Wales, 1 from South Australia, and 1 from Australian Capital Territory. When asked to describe where they live 34.4% reported that they live in a capital city or inner urban area, 31.3% live in an outer suburban area, 21.9% live in a regional centre, and 12.5% live in a rural area.

Health and HIV

People were asked about their sense of well-being and general health as well as the effects of HIV. We found that, while many people with Haemophilia are living with HIV related illness or other major health concerns, around two thirds (65.5%) feel good about their general health and are actively doing things to improve their health. This includes getting adequate sleep (76.7%), taking pills on time (76.1%), relaxation (65.3%), exercise (61.9%) and a good diet (58.3%).

Around one third of people with Haemophilia have been diagnosed with an AIDS defining illness at some point, but this has happened less in the last two years. This suggests that anti retroviral treatments have been successful in slowing the progression to AIDS in many people. However, one in five people with Haemophilia (18.5%) have already experienced an illness or condition related to HIV. Those of most concern to people include sleep disorders (41.7%), weight loss (30.2%), confusion or memory loss (24.0%) and Lipodystrophy (changes in fat distribution on the body – 21.9%).

All people with Haemophilia were actively monitoring their health through regular CD4/T-cell tests and viral load tests (which measure immune system damage and amount of virus in the body). At the time of their most recent tests, people with Haemophilia had CD4 counts and viral loads comparable to the rest of the sample. The results of their most recent tests are

shown in Table 1 below. Only two of the 27 people with Haemophilia for whom both CD4 and viral load data were available had both high viral load and severe immune damage.

Table 1 Results of serological testing

Description	Result	Proportion
CD4/T-cell count	cells/ml blood	
little or no immune damage	over 500	44.4
moderate immune damage	250 - 500	35.9
severe immune damage	below 250	19.7
Viral load	copies/ml blood	
below detectable level	below 200 / 500	54.5
low	500 - 10,000	27.3
moderate	10,000 - 50,000	9.1
high	over 50,000	9.1

When asked who they usually see for HIV related treatment, people with Haemophilia were significantly more likely than other PLWHA to identify a HIV specialist (54.5% versus 29.7%) or a hospital outpatient clinic (18.2% versus 9.4%) and less likely to identify a HIV GP (9.1% versus 38.9%). For general (non-HIV) medical treatment, people with Haemophilia were less likely than other PLWHA to see a HIV GP (18.2% versus 46.1%) and more likely to see a HIV specialist (27.3% versus 14.5%) or to visit a hospital outpatient clinic (18.2% versus 6.5%).

Other physical problems

The issue of co-infection is of growing concern to PLWHA and HIV service providers. Just over 65.9% of people with Haemophilia are living with both HIV and hepatitis C. People infected with both viruses face greater difficulties in treatment choices and more uncertainty about how HIV develops in the body.

Mental health and support

Mental health is a growing concern in the HIV scene. Depression, anxiety, dementia and other related problems are important health issues.

The research found that in the last 6 months around one in five people with Haemophilia (22.7%) had been taking medicine for depression (13.1%) or anxiety (22.7%). More than 42.9% were using the counselling services available at HIV/AIDS organisations and other agencies.

Overall, most people with Haemophilia have reasonable levels of support from their social networks, although 18.1% didn't get 'a lot' of support from anyone. The richest sources of support came from partners/spouses, close friends, parents and pets.

HIV treatments

Over the last few years treatment options have developed to a point where many people living with HIV/AIDS have been able to imagine a future where HIV shifts from a life-threatening

disease to an on-going illness that can be controlled. However, the reality of treatments is very complex. Drug side effects, the demands of treatments and concerns about future treatment options concern many people.

Most people with Haemophilia (73%) are currently using antiretroviral therapy (ARV) and this is very similar to the rest of the Futures II sample. More than half (60.0%) are experiencing side effects including diarrhoea and nausea. Almost half (48.2%) have problems managing the treatment, including remembering to take medication on time (57.1%) and organising meals around medication (36.3%). Despite these problems most people (81.2%) had not missed doses in the past two days.

While one in four people with Haemophilia are not currently using ARV, most of these people have done so in the past. Most commonly this group had stopped because of side effects or to have a break from the drugs. Only 11.2% of people had never used ARV, and most of these people would consider using it in the future if needed.

Whether they are currently using ARV or not, around one fifth (18.1%) of people with Haemophilia have taken a break from treatments at some point in the past, either to clean out their system or have a drug holiday.

Most people with Haemophilia (72.7%) are cautiously optimistic about ARV treatment and believe it offers people with HIV/AIDS a better future. Overall, the attitudes toward antiretroviral drugs expressed by people with Haemophilia do not differ from the attitudes expressed by other PLWHA.

Some form of complementary/alternative therapy, particularly vitamin and mineral supplements, massage, meditation and acupuncture, is used by more than half of people with Haemophilia (55.7%). Most of these people (69.6%) believe that these therapies can improve their well being, and over half believe complementary/alternative therapy have a role in delaying the development of HIV illnesses (56.5%) and reducing side effects of ARV (51.7%). Overall, the attitudes toward complementary therapies expressed by people with Haemophilia do not differ from the attitudes expressed by other PLWHA.

Table 2 Use of antiretroviral drugs, prophylaxis for opportunistic infection (OI) and alternative therapies

	People with Haemophilia	People without Haemophilia
Using antiretroviral drugs	73.4%	73.6%
Using OI prophylaxis	52.1%	32.7%
Using alternative therapies	55.7%	55.6%

Sex and relationships

Handling sex and relationships while living with HIV is a major issue for people living with HIV/AIDS. Less than half of the respondents with Haemophilia said they were currently in a regular relationship (41.9%). Table 3 shows that a high number of people with Haemophilia were not having any sexual relationships at the time of the survey, however, this was not significantly different from the rest of the survey population.

Table 3: Type of sexual relationship(s)

Sexual relationships	People with Haemophilia	People without Haemophilia	Total
No sex at present	45.5	25.2	25.4
Regular relationship only	36.4	25.4	25.5
Casual sex only	18.2	28.8	28.7
Regular relationship plus casual sex	0.0	18.1	17.9
Regular with two or more people	0.0	2.5	2.5

Around one third of those people with Haemophilia in a regular relationship have a spouse or partner also living with HIV/AIDS (34.3%). All of these people have told their regular partner about their HIV, usually when they were diagnosed, or when they started the relationship. In most cases the response was supportive.

Due to the small numbers of people with Haemophilia who are sexually active it is not possible to do any statistical analysis of their condom use or comparisons with other groups of PLWHA. Of those few who are in sero-discordant relationships (where their partner is HIV negative) condoms were always used for vaginal and anal intercourse in the last six months. Unprotected vaginal and anal intercourse occurs primarily with HIV positive partners (sero-concordant relationships).

The vast majority of people with Haemophilia agreed with the statement that *Few people would want a relationship with someone who has HIV* (81.7%) and three quarters (77.5%) were afraid of infecting their current or future partners. Around two thirds of people with Haemophilia (63.0%) felt that HIV had a negative effect on their sexual pleasure and over half (51.8%) agreed with the statement *I am afraid of telling potential partners of my HIV status in case they reject me*. Over half (56.1%) did agree that *People with HIV now have a better chance to form partnerships and relationships*.

Only a small number of people with Haemophilia (11.9%) said they had dependent children. Respondents were also asked if they were considering having a child in the future. Table 4 presents the responses to this question.

Table 4: Considering having a child

	%
No	84.3
I have decided to have a child/children in the future	6.0
I have thought about it but I haven't decided	4.8
I have thought about it but I have decided that it is too risky	4.8

Recreational drugs

People were asked about their use of non-prescription drugs, both those legally available and those currently banned in Australia.

Alcohol is the most commonly used recreational drug by people with haemophilia (70.9%) and one third of people with Haemophilia (33.5%) smoke cigarettes. The most commonly used illegal drug was marijuana used by around one third of people with Haemophilia (36.2%)

Very few people with Haemophilia reported using other recreational drugs such as amyl (three people), ecstasy (one person), LSD (one person) and cocaine (not injected – one person).

Only two people with Haemophilia had injected drugs in the last 12 months. However neither of these men had shared needles in the past 12 months.

Discrimination

Concerns about discrimination are an everyday issue for PLWHA. One quarter of people with Haemophilia (25.9%) felt they had received less favourable health services because of their HIV and 14.5% have had problems in their workplace.

Well over half of people with Haemophilia (57.5%) said their HIV status was disclosed to another person when they didn't want it to be.

HIV community life and information

Over half (53.1%) of people with Haemophilia had some contact with HIV/AIDS organisations and this is significantly less than the 78.9% of people without Haemophilia who completed the survey and said they had some contact with an HIV/AIDS organisations. People with Haemophilia said they used HIV/AIDS organisations mostly for treatment advice, social contact, peer support and counselling.

Over half of the people with Haemophilia spent a little time (24.7%) or a lot of time (26.3%) with other PLWHA. More than three-quarters (78.5%) of people with Haemophilia have had someone close to them die of AIDS. A small number (15.6%) have been involved in the nursing and care of someone with AIDS in the last two years.

Table 5 below shows that for information about both treatments for HIV/AIDS and living with HIV/AIDS, the most commonly cited sources of information were the respondent's doctor who specialises in HIV treatment and the Haemophilia Foundation.

Table 5 Sources of information about HIV/AIDS for people with Haemophilia

	Important for information about	
	treatments for HIV/AIDS	living with HIV/AIDS
Doctor who specialises in HIV	(93.2%)	(56.5%)
Haemophilia Foundation	(53.9%)	(38.4%)
HIV/AIDS newspapers and magazines	(37.5%)	(41.3%)
Other Doctor	(36.6%)	(18.1%)
HIV/AIDS Organisation staff	(28.2%)	(30.6%)
Pharmacist	(27.6%)	(15.2%)
Treatments Officer at HIV/AIDS organisation	(25.0%)	(12.2%)
Nurse	(23.5%)	(22.3%)
HIV-positive friends	(15.2%)	(18.4%)

Compared to other respondents, people with Haemophilia nominated different people as important sources of information. For information about treatments for HIV/AIDS, people with Haemophilia were significantly more likely than other PLWHA to seek information from the Haemophilia Foundation, and significantly less likely to seek information from HIV/AIDS newspapers and magazines and articles in gay press. For information about living with HIV/AIDS, people with Haemophilia were significantly more likely than other PLWHA to seek information from the Haemophilia Foundation, and significantly less likely to seek information from HIV-positive friends and articles in gay press.

Employment

HIV infection has significantly disrupted people's working lives and career development. More than one third (37.2%) of people with Haemophilia had stopped work at some time in the past due to the impact of HIV on their emotional or physical health. Low energy, poor health, expecting illness and stress, depression and/or anxiety were the most commonly listed reasons for stopping work.

Of those people who had left work in the past, 35.4% have since returned to work. People with Haemophilia returned to work for a variety of reasons including financial reasons, to do something worthwhile, for something to do, because of better physical health or better psychological health, the possibility of flexible working hours or the possibility of working part-time.

One third (32.1%) of people with Haemophilia are currently in paid employment, and of these people most are working full time. Workers also reported experiencing moderate to high stress levels. It is important to note that in 1997 the first HIV Futures Survey found that

people with Haemophilia were significantly less likely than other PLWHA to be currently working. In 1999 the second HIV Futures Survey found that there were no significant differences between people with Haemophilia and other PLWHA who are currently working.

Overall, 49.4% workers had not disclosed their HIV status to anyone in their workforce and 14.5% said they had experienced less favourable treatment than other people at work as a result of having HIV/AIDS.

Finances

One quarter (25.8%) of people with haemophilia are living below the poverty line although this is notably lower than in 1997 when 44% of people with Haemophilia reported an income below the poverty line. Almost two thirds (62.1%) of this population are primarily dependent on a government benefit or pension, 29.1% said their main source of income was a salary, 6.3% said superannuation, savings/annuity and 2.6% said family/friends support me.

Respondents were asked to indicate whether or not in the six months prior to completing the survey they had experienced any difficulty meeting the costs of daily living. Responses from people with Haemophilia indicated that:

- 59.9% had difficulty meeting the cost of utilities (telephone/electricity/gas/water);
- 59.5% had difficulty meeting the cost of travel/holidays;
- 57.8% had difficulty meeting the cost of clothing;
- 56.4% had difficulty meeting the cost of transport;
- 52.8% had difficulty meeting the cost of food;
- 48.9% had difficulty meeting the cost of going out (eating/drinking);
- 41.2% had difficulty meeting the cost of entertainment;
- 40.9% had difficulty meeting the cost of other prescribed medication;
- 39.3% had difficulty meeting rent/mortgage/housing costs; and
- 34.7% had difficulty meeting the cost of co-payments for medication for HIV/AIDS;

As was the case with the rest of the sample of PLWHA, people with Haemophilia reported difficulty meeting the costs of daily living and this was not necessarily a consequence of having an income below the poverty line.

Discussion

The experiences of HIV positive people with Haemophilia are similar in many important ways to other PLWHA. In terms of treatment uptake and experiences of treatment (including side effects, treatment breaks and attitudes to treatment), health status and monitoring, mental health and social support, sex and relationships, the experiences of people with Haemophilia do not differ substantially from other HIV positive Australians. This shared experience of HIV positivity is important to remember when the mode of infection becomes the basis for divisive treatment of PLWHA.

The differences for HIV positive people with Haemophilia are mostly in their access to health and community services. People with Haemophilia are less likely to utilise HIV GPs and are more likely to manage their HIV through specialists and hospitals. They are also less likely to be involved in AIDS community organisations. These differences in the mode of engagement with the epidemic highlight the importance of Haemophilia organisations and groups in the provision of information and support to HIV positive people with Haemophilia.

People with Haemophilia are also significantly more likely to be Hepatitis C positive, something that, particularly in the long term, has important implications for the efficacy of antiretroviral treatments, and the management of general health. It is critical that the voices of HIV positive people with Haemophilia continue to be heard in the debates around treatment issues.

Copies of the document HIV Futures II: The Health and Well-Being of People with HIV/AIDS in Australia can be obtained from the Australian Research Centre in Sex, Health and Society, La Trobe University by calling (03) 9285 5382. A copy of the full report is also on the web site:

www.latrobe.edu.au/hiv-futures

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