

# **HIV FUTURES II**

## **Living with HIV when co-infected with hepatitis C**

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## FOREWORD

This is the first study from the Living with HIV Program at ARCSHS that specifically examines the experiences of living with HIV when also co-infected with hepatitis C. It is also the first such examination of people co-infected with HIV and hepatitis C in Australia. Arising from the National HIV Futures II survey, this report concentrates its focus on aspects of living with HIV – and thus does not interrogate the very important aspects of people's experiences of managing the social and clinical aspects of having hepatitis C. We intend this will be a specific topic for future work within the program.

Internationally there has been an increasing concern with the implications of being co-infected with HIV and hepatitis C. The current estimate in Australia is that approximately 14% of people living with HIV/AIDS (PLWHA) also have the hepatitis C virus (Dore, 1998).

In addition to co-infected PLWHA being a significant minority of Australians with HIV, there are a range of other reasons why understanding experiences of co-infection is being seen as a priority. The improvements in disease progression and life expectancy due to antiretroviral (ARV) treatments have meant that the serious longer-term effects of hepatitis C, such as liver disease, now, in a sense, come to the fore. Hepatitis C co-infection adds considerable complexity to clinical management of HIV in that a number of ARV treatments result in liver toxicity (see AFAO/NAPWA, 2000a for an updated list).

There is a sizeable literature on the clinical implications of HIV and hepatitis C co-infection in terms of progression of each of the diseases. The suggestion from the clinical literature is that PLWHA co-infected with hepatitis C are likely to progress faster to end stage liver disease. The specific impact on HIV progression is more contested. People interested in a review of this literature are referred to a recent Australian publication by Mijch (2001).

While publications from community organisations (AFAO 1998, AFAO/NAPWA 2000b, Straight Arrows 2001) have noted for some time the importance of the specific experience of co-infection, in fact to date there has been no social research on this topic. The analysis that preceded this report combined with consultations with stakeholders, has already resulted in further questions specifically on hepatitis C being included in the current HIV Futures 3 study. In addition, the Living with HIV program at ARCSHS plans an in-depth study of the experiences of HIV and hepatitis C co-infection.

This report then is a beginning. It examines the specific experiences of living with HIV for the 17% of the HIV Futures II sample who also reported being co-infected with hepatitis C.



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Full details of FUTURES II and other projects within the Living with HIV program can be found at [www.latrobe.edu.au/hiv-futures](http://www.latrobe.edu.au/hiv-futures).

## EXECUTIVE SUMMARY

Of the total HIV Futures II sample of 924, 17% reported being co-infected with hepatitis C. Based on Dore's (1998) estimate that 1,555 Australians are living with HIV and hepatitis C, this survey reports on information from approximately 10% of the co-infected population in Australia.

The co-infected sample of PLWHA were significantly younger than other PLWHA (39.5 years v 42.6), had a larger proportion of women (14%), had been HIV positive for longer (9.7 years v 8.6 years), and were more likely to report injecting drug use (IDU) or haemophilia as their mode of HIV infection. Some 48% of co-infected PLWHA reported IDU in the previous 12 months, and a further 30% reported IDU more than 12 months ago. This compared to 9% reporting IDU in the previous 12 months, and a further 9% reporting IDU more than 12 months ago for the broader sample. Twenty-four percent of the co-infected participants had taken prescribed methadone in the previous 12 months (compared to 2% of the rest of the sample).

In terms of health, co-infected PLWHA did not rate their health differently from their peers, and a similar proportion reported an AIDS defining illness. Similarly, there were no differences for co-infected PLWHA in terms of the results of their last CD4/t-cell and HIV viral load counts.

Co-infected PLWHA were less likely to report experiencing lipodystrophy, but more likely to report weight loss, sleep disorders and memory loss. PLWHA with hepatitis C were significantly more likely to report having hepatitis B (45% v 36%) and more likely to report having had hepatitis A (38% v 28%), although this difference was not statistically significant.

One of the very important findings from this report is in relation to co-infected PLWHAs experiences of antiretroviral (ARV) treatment. While a similar proportion of co-infected PLWHA, had ever tried ARV treatment, a significantly lower proportion were currently on ARV treatments (58% v 77%). Those co-infected PLWHA who had stopped ARV, had done so longer ago (3.4 years v 1.5 years) and were less inclined to say that they would consider ARV in the future. While we were unable to detect any differences in the reasons for ceasing ARV in comparison to other PLWHA, we note that the co-infected sample were more likely to state that ARV had led them to cease work, and less likely to state that ARV had enabled them to re-commence work. Like their peers, 78% of the co-infected PLWHA who were taking ARV reported difficulties with taking medications. The main issues that caused difficulty were remembering the timing of doses, organising doses around meals and the large number of tablets that needed to be taken.

A significantly lower number of coinfected PLWHA cited doctors specialising in HIV as the *most* important source of information about *treatments* (63% v 77%). For co-infected respondents, HIV/AIDS organisation staff were cited by 25% as the *most* important source of information about living with HIV/AIDS. Despite getting information from a wider range of sources co-infected PLWHA were significantly more likely than other PLWHA to feel they lack information when making

decisions about using antiretroviral treatments (22% v 14%), interactions between antiretroviral treatments and other medications (30% v 20%), recreational (party) drug use (26% v 15%), legal issues (24% v 16%), and having children (12% v 5%).

In terms of other health maintaining behaviours, 58% of co-infected respondents were using complementary or alternative therapies. Co-infected PLWHA actively engaged in a range of activities to improve their health.

In terms of social support and connectedness, co-infected PLWHA were no different to other PLWHA in their ratings of social support or on items indicative of depression. Co-infected respondents were more likely to be in contact with HIV organisations, and reported utilising a wider range of services and information sources on treatments. While reporting lower levels of alcohol consumption than other PLWHA or the general population, co-infected respondents reported different patterns of drug use, including higher usage of cigarettes, marijuana and injected heroin or injected cocaine, and lower reported use of amyl and non-injected speed.

Another important set of findings from this research concerns discrimination and disadvantage. Co-infected PLWHA were significantly more likely than their peers to report experiences that indicate they suffer both discrimination and disadvantage. More co-infected PLWHA had experienced: disclosure of their HIV status without permission (76% v 57%), less favourable treatment at a medical service (49% v 28%), discrimination at work due to HIV status (31% v 19%). The negative impact of HIV diagnosis on work was reported by more co-infected PLWHA, with 70% of co-infected PLWHA who have ever worked reporting having stopped work at some stage due to their HIV diagnosis. This was a significantly greater proportion than that reported by other PLWHA (58%).

Co-infected PLWHA were also more likely to be living below the poverty line, not currently in paid employment, living on a government benefit and in less stable housing arrangements.

So what can we conclude from this examination? Firstly we can see that while many aspects of living with HIV are shared regardless of ones hepatitis C status, there appear to be some issues that are likely to affect co-infected PLWHA more than their peers.

Importantly for future work within the program we note that we have little or no information specifically on what is happening for people in terms of managing their lives and health in relation to having hepatitis C. Data from HIV FUTURES 3 will begin to explore these questions.

The fact that co-infected PLWHA have different experiences from other PLWHA, and the findings that many experiences are shared regardless of hepatitis C co-infection status, have important implications for responses by community organisations (both HIV specific and hepatitis specific) and for those involved in clinical and health management.

It is vital that we increase our understandings of not just the impact of one virus on another, but also the synergistic effects - both clinically and socially of living with both viruses.

## THE HIV FUTURES II SURVEY

The HIV Futures II survey was an anonymous self completed mail back questionnaire which explored Australian PLWHA experiences in eight domains: demographic characteristics; accommodation; health and treatments; services and organisations utilised; sex and relationships; employment; recreational drug use; and finances. 924 respondents completed the survey in 1999. This sample represents 8% of all PLWHA in Australia. The results relating to the total sample and a detailed description of the community consultations and recruitment methods for the overall study are reported in the document *HIV Futures II: The Health and Well-Being of People with HIV/AIDS in Australia* (Grierson, Bartos, de Visser and McDonald, 2000). The overall sample under-represents gay men from NSW and over-represents women, heterosexual men, those from non-metropolitan areas and those from outside NSW. All data in the remainder of this report have been weighted based on mode of infection, gender, state of residence and diagnoses of AIDS defining illness in order to conform to the demographic profile detailed in the Australian HIV Surveillance report.

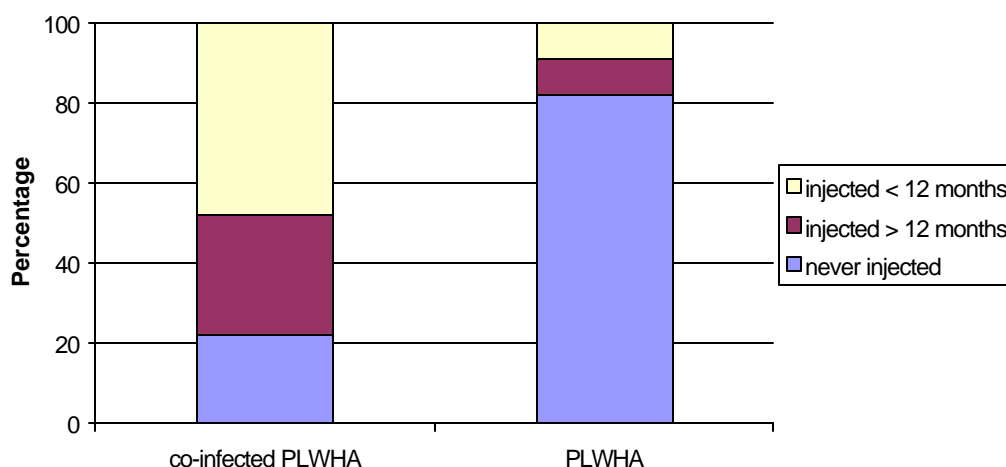
The results below report on analysis of the experiences of PLWHA co-infected with hepatitis C from the HIV Futures II survey.

### Demographic characteristics

Seventeen percent of PLWHA who completed the HIV Futures Survey reported being co-infected with hepatitis C. Among these respondents, 86% were male and 14% were female. The ages of co-infected respondents ranged from 24 years to 73 years. The average age for co-infected PLWHA was 39.5 years, making them significantly younger than the rest of the sample (mean age=42.6). On average, PLWHA co-infected with hepatitis C had been HIV seropositive for 9.7 years - a significantly longer time than that reported by those PLWHA who hadn't been diagnosed with hepatitis C (mean=8.6 years).

Co-infected respondents had been infected with HIV most commonly through sexual contact: 49% cited homosexual or bisexual contact as the most likely transmission route, 20% reported injecting drug use, 9% cited heterosexual contact, 5% reported homosexual/bisexual contact and injecting drug use; 5% were infected by blood products or in a health care setting; and 13% were people with haemophilia infected through contaminated blood products. Compared with other PLWHA, PLWHA with hepatitis C were significantly more likely to report injecting drug use and haemophilia as their mode of infection, and significantly less likely to report homosexual sex as their mode of infection.

Forty-eight percent of co-infected PLWHA reported injecting drug use (IDU) in the previous 12 months, and a further 30% reported IDU more than 12 months ago. This compared to 9% reporting IDU in the previous 12 months, and a further 9% reporting IDU more than 12 months ago for the broader sample. Twenty-four percent of the co-infected participants had taken prescribed methadone in the previous 12 months (compared to 2% of the rest of the sample).



**Figure 1** Injecting drug use history by co-infection status

### Current health

Most respondents reported that they currently feel healthy: 15% describe their health as “*excellent*”, 54% describe their health as “*good*”, 27% describe their health as “*fair*”, and 4% describe their health as “*poor*”. Twenty percent of the co-infected respondents have been diagnosed with an AIDS-defining illness. These proportions are similar to those reported by the rest of the sample.

Almost two-fifths (37%) of co-infected respondents have a major health condition other than HIV/AIDS and hepatitis C - a similar proportion to that reported by the rest of the sample. The most frequently cited “other” health condition was haemophilia (13% of those co-infected respondents with another major health condition). Those who were co-infected with HIV and hepatitis C were significantly less likely to be experiencing lipodystrophy at the time of the survey (12% v 32%), but were more likely to be experiencing weight loss (44% v 32%), sleep disorders (57% v 42%), or confusion and memory loss (40% v 29%). PLWHA who had been diagnosed with hepatitis C were significantly more likely to have been diagnosed with hepatitis B (54% v 36%), were slightly (but not quite significantly) more likely to have had hepatitis A (38% v 28%).

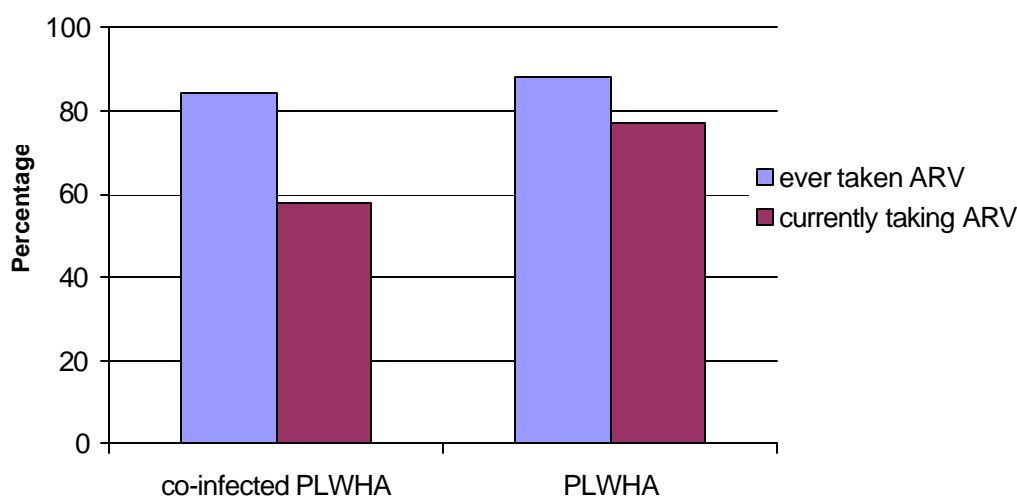
Nearly all of the co-infected respondents have taken a CD4/T-cell test (99%) and an HIV viral load test (99%). The results of respondents’ most recent CD4/T-cell tests and HIV viral load tests are displayed in Table 1 (below). There were no significant differences between co-infected respondents and the rest of the sample on their most recent test results. However, it is interesting to note that over one in ten (12%) of co-infected PLWHA has a moderate or high HIV viral load (above 10,000) and severe immune system damage (CD4 count below 250).

**Table 1** Results of serological testing for co-infected PLWHA

| Description                | Result                 | Percentage |
|----------------------------|------------------------|------------|
| <b>CD4/T-cell count</b>    |                        |            |
|                            | <b>cells/ml blood</b>  |            |
| little or no immune damage | over 500               | 40         |
| moderate immune damage     | 250 - 500              | 37         |
| severe immune damage       | below 250              | 24         |
| <b>HIV Viral load</b>      |                        |            |
|                            | <b>copies/ml blood</b> |            |
| below detectable level     | below 200 / 500        | 54         |
| Low                        | 500 - 10,000           | 16         |
| Moderate                   | 10,000 - 50,000        | 14         |
| High                       | over 50,000            | 16         |

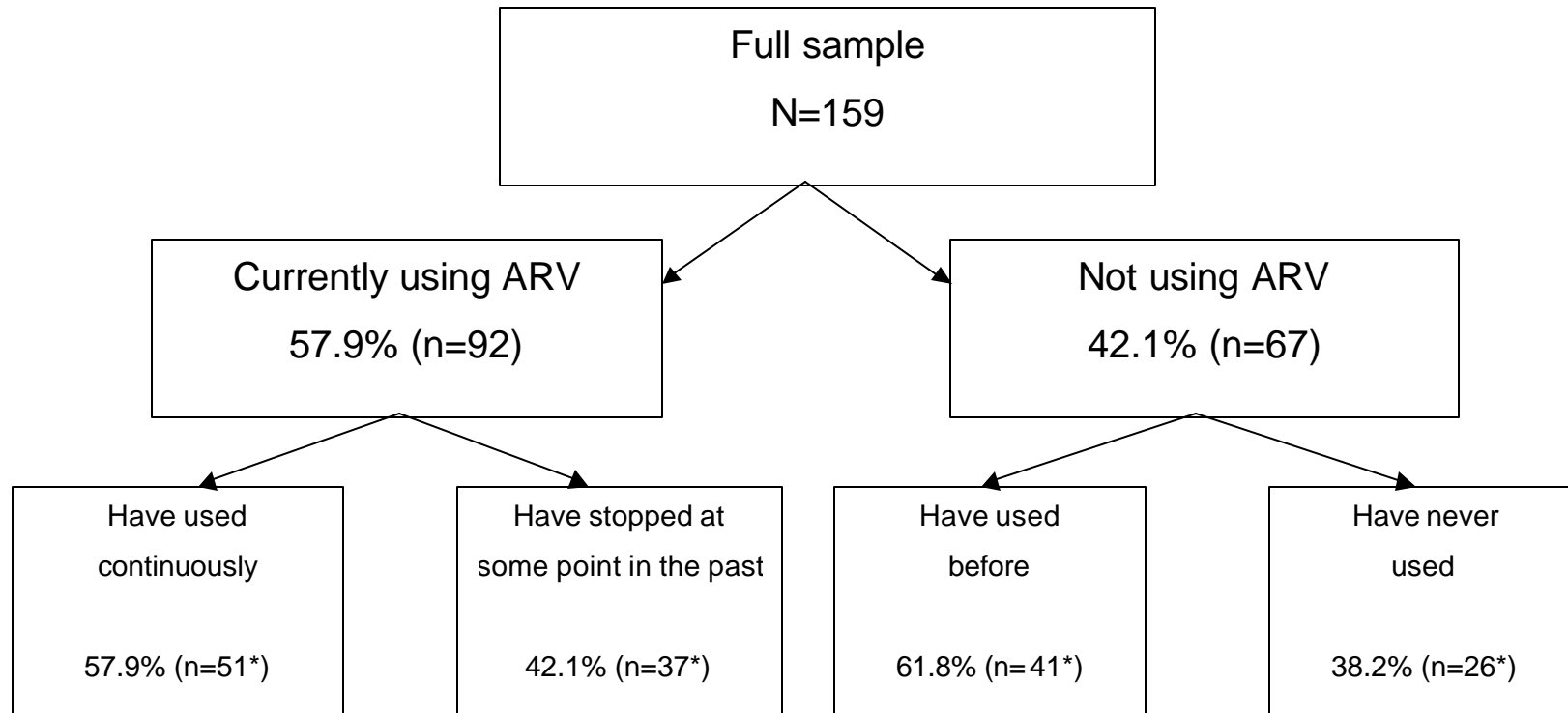
**Antiretroviral treatment for HIV/AIDS**

Co-infected PLWHA were just as likely as other respondents to have to have taken antiretroviral treatments at some stage, but they were significantly less likely to be using them now (58% v 77%) (see Figure 2 below).



**Figure 2** ARV uptake by co-infection status

Figure 3 (next page) details co-infected PLWHA's history of using antiretroviral treatments. This figure shows that for those co-infected PLWHA who are not currently using antiretroviral treatments, 62% have used them in the past and 38% had never used them before. For those who are currently using antiretroviral treatments, 42% had stopped using them at some point in the past, and 58% had used the treatments continuously.



**Figure 3** The uptake of antiretroviral treatment for co-infected PLWHA

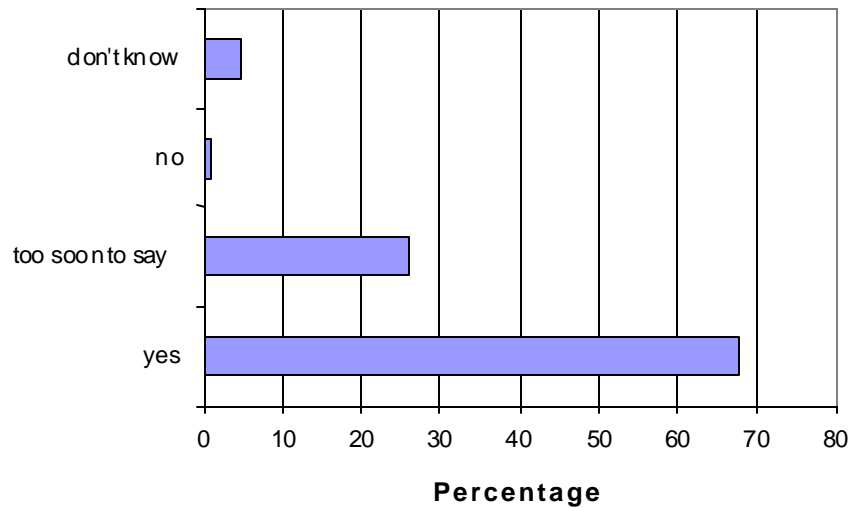
\* discrepancies in sub-totals are due to missing data

Of those co-infected respondents who are currently taking antiretrovirals 41% report that their health has improved while taking the medication, 22% reported that their health has stayed the same, 34% that it fluctuated, and 3% that it has deteriorated. These proportions are similar to those reported by other respondents. Most (71%) of the co-infected respondents who use antiretroviral treatments reported that they experience side-effects - a similar figure to that reported by other PLWHA. The most commonly reported side effects from antiretroviral treatments are: diarrhoea (experienced by 36% of co-infected respondents experiencing side effects of antiretroviral treatments), nausea (33%), insomnia (24%), fatigue/lethargy (14%), headaches (16%) and loss of appetite (17%).

Three-quarters (78%) of co-infected respondents who use antiretrovirals report difficulties in taking this medication – a similar proportion to other PLWHA currently taking antiretrovirals. The most common difficulties among these respondents are remembering to take drugs on time (53%), organising meals around medication (32%) and taking a large number of tablets (28%).

Over one in ten (14%) co-infected respondents missed at least one dose on the day before they filled out the survey, with a similar proportion (15%) missing a dose the day before that. Only 3% missed a dose on both days. Forty-two percent of co-infected respondents have taken a break from antiretrovirals at some stage, a similar proportion to that for other PLWHA. The reasons most commonly given for taking a break are side effects (22% of those currently using antiretroviral treatment), taking drugs at the right time was too difficult (11%) and to have a drug holiday (11%).

Respondents were asked to rate their agreement with a number of statements about combination antiretroviral therapy on a scale of 1='strongly disagree' to 4='strongly agree'. The only significant difference found on these items was that co-infected respondents (mean=2.16) disagree less strongly than other respondents (mean=1.85) that they were healthy now and didn't need to use combination antiretroviral drugs. Figure 4 (below) shows that most (68%) co-infected respondents agree that antiretroviral drugs have improved the prospects of most PLWHA, while 26% believe it is too soon to tell, and 5% do not know if antiretroviral drugs have improved the prospects of most PLWHA. Only two co-infected respondents (1%) think that antiretroviral drugs have not improved the prospects of PLWHA.



**Figure 4** Opinions of co-infected respondents on whether antiretrovirals have improved the prospects of PLWHA

Those co-infected respondents that are currently using combination therapy have been doing so for an average of 2 years and 11 months. The mean number of combinations they have tried in this time is 2.5, with a mean of 1.4 of these having been used in the past 12 months. They started on these treatments when their HIV viral load was high (mean = 362559.9 copies/ml) and their CD4 count was low (mean = 236.4). The most common circumstances surrounding the commencement of combination antiretroviral therapy for these respondents were doctors advice (90%), a big drop in CD4 count (44%), a rise in HIV viral load (41%), hearing of the effectiveness of the treatment (40%), and new drugs becoming available (38%). Co-infected respondents were significantly more likely to start on combination therapies due to a big rise in HIV viral load.

For those who have tried more than one combination of antiretrovirals the most common reasons for changing the last time they did so were: side effects (54%), the combination they were changing from not working (17%), and resistance to their combination having developed (15%). Most felt they still had options left – 46% reporting they have many options, 50% a few, 2% one and 2% none.

Those co-infected respondents who have stopped using antiretrovirals had been using them for an average of 1 year and 8 months and had stopped an average of 3 years and 4 months ago – significantly longer ago than the 1 year and 5 months ago reported by other respondents. They had also used significantly fewer combinations on average than other respondents (mean=2.5 v mean=3.0).

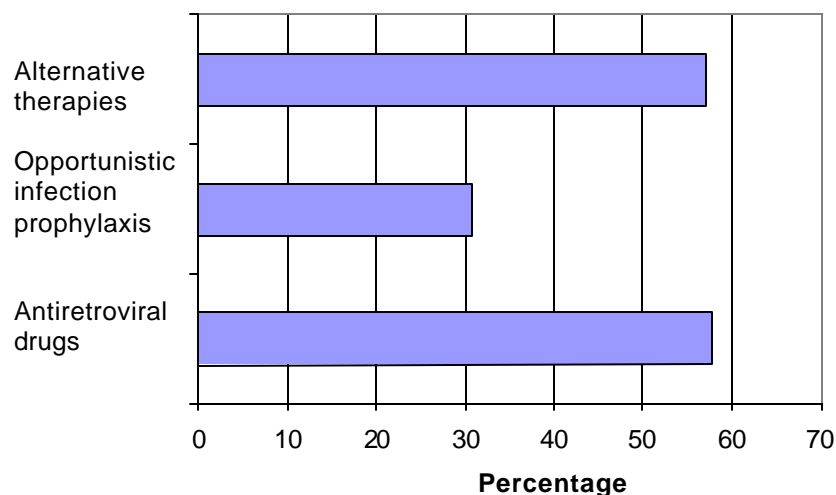
Of the 41 co-infected respondents who had taken antiretrovirals and stopped, only two respondents (5%) reported that their health improved on the medication, 16% reported that it stayed the same,

37% that it fluctuated and 42% that it deteriorated. The most common reasons for stopping use of antiretrovirals were side effects (75%), that they weren't working (36%), they didn't fit in with the respondent's life style (32%), taking drugs at the right time became too difficult (30%), taking a break to clean out the respondent's system (25%), drug resistance having developed (26%) and having a drug holiday (16%). These proportions are similar to those reported by other respondents who had stopped taking antiretroviral drugs.

Seventy-seven percent of all co-infected respondents not currently taking antiretrovirals reported that they would consider taking them in the future – a significantly lower proportion than the 90% reported by other PLWHA. The most common circumstances these co-infected PLWHA report that would lead them to re-commence or start antiretrovirals again were: becoming very ill (67%), a significant drop in CD4/T-cell count (63%), hospitalisation due to HIV-related infections (61%), a significant rise in HIV viral load (60%), on a doctor's advice (46%), or if new drugs became available (39%).

### Other treatments for HIV/AIDS

Figure 5 (below) shows that the majority of co-infected PLWHA use antiretroviral drugs and most use alternative therapies. However only 30% of co-infected PLWHA use prophylaxis for opportunistic infections - prophylaxis for *Pneumocystis carinii* pneumonia (PCP) and/or prophylaxis for other opportunistic infections.



**Figure 5** Use of therapies for HIV/AIDS for co-infected respondents

**Health maintenance**

As shown in Figure 5 above, over half (57%) of the co-infected respondents use complementary or alternative therapies for HIV/AIDS. This was similar to the proportion reporting the use of complementary or alternative therapies by the rest of the sample. The most commonly used complementary/alternative therapies are vitamin/mineral supplements (83% of co-infected respondents who use alternative therapies), massage (53%), meditation/visualisation (49%), and herbal remedies (34%). Among those who use alternative therapies, co-infected respondents were more likely to use meditation.

In the last 6 months the health services that co-infected respondents had most commonly used were a GP who specialises in HIV (53%), an HIV organisation clinic (46%), specialist/physician (44%), a hospital outpatient clinic (32%), an HIV hospital social worker/counsellor (26%), a sexual health centre (21%), an AIDS organisation social worker (23%), a hospital inpatient clinic (12%), and an employment agency (7%).

Co-infected respondents were significantly more likely to have used an HIV organisation clinic and a hospital social worker than other respondents. Co-infected respondents had to go to significantly more places (mean=1.59) on average than other respondents (mean=1.43) to get all their prescriptions filled.

**Information and support services**

Co-infected respondents are significantly more likely to have direct contact with an HIV/AIDS-related organisation (89% v 77%), and were significantly more likely to have held a decision making position in such organisations (41% v 29%). Of those co-infected respondents in contact with HIV/AIDS organisations, 67% receive a newsletter, 77% are clients, 42% are members, 17% are staff, and 15% are volunteers. Of those co-infected respondents who do not have contact with an HIV/AIDS organisation, the most common reason given is not wanting to be involved (75%).

**Table 2** Percentage of co-infected PLWHA using services provided by HIV/AIDS-related organisations and other service organisations

| <b>Service</b>                  | <b>HIV/AIDS organisation</b> | <b>Other service organisation</b> |
|---------------------------------|------------------------------|-----------------------------------|
| Treatments advice               | 52                           | 25                                |
| Social contact with other PLWHA | 51                           | 20                                |
| Financial assistance            | 38                           | 21                                |
| Peer support group              | 38                           | 13                                |
| Counselling                     | 36                           | 29                                |
| Alternative therapies           | 33                           | 27                                |
| Housing assistance              | 31                           | 32                                |
| Informal peer support           | 28                           | 16                                |
| Legal advice                    | 24                           | 20                                |
| Financial advice                | 23                           | 22                                |
| Pharmacy services               | 21                           | 46                                |
| Respite care                    | 21                           | 16                                |
| Library                         | 17                           | 28                                |
| Drug/alcohol treatment          | 16                           | 30                                |
| Mental health services          | 14                           | 27                                |
| Internet access                 | 13                           | 22                                |
| Return to work skills           | 8                            | 20                                |
| Employment services             | 7                            | 19                                |

Table 2 (above) displays the percentage of co-infected respondents who use each of the services provided by both HIV/AIDS-related organisations and then other service organisations. The data show that co-infected respondents use HIV/AIDS-related organisations for a wide range of services. Indeed, co-infected respondents make use of a wider range of services than other PLWHA. Co-infected respondents were significantly more likely to report that they use HIV/AIDS organisations for financial advice, financial assistance, social contact with other PLWHA, alternative therapies, respite care, housing assistance, employment services, drug/alcohol treatment, mental health services, and library services. They are also more likely than other PLWHA to use non-HIV/AIDS organisations for counselling services, financial assistance, peer support groups, social contact with other PLWHA, pharmacy services, respite care, housing assistance, return to work skills, drug/alcohol treatment, mental health services, and library services.

Respondents were asked to indicate which people and/or organisations they rely upon for both information about treatments for HIV/AIDS and information on living with HIV/AIDS. Their

responses are shown in the Table 3. The most commonly cited source of information about treatments for HIV/AIDS was a doctor specialising in HIV. However, in gathering treatments information, over two thirds of the respondents rely on HIV/AIDS-related newspapers and magazines, and just under half rely on HIV positive friends and the gay press, which suggest that co-infected PLWHA seek information from a range of different sources. Co-infected respondents were significantly more likely than other PLWHA to report that alternative therapists, treatments officers, other HIV/AIDS organisation staff and injecting drug users' organisations are an important source of information about treatments. They were also less likely to report that doctors specialising in HIV, are an important source of information about treatments.

The sources of information about living with HIV/AIDS most frequently cited as being important were HIV magazines and newspapers and HIV positive friends. Co-infected respondents were more likely than other PLWHA to cite alternative therapists, and injecting drug users' groups as an important source of information on living with HIV/AIDS.

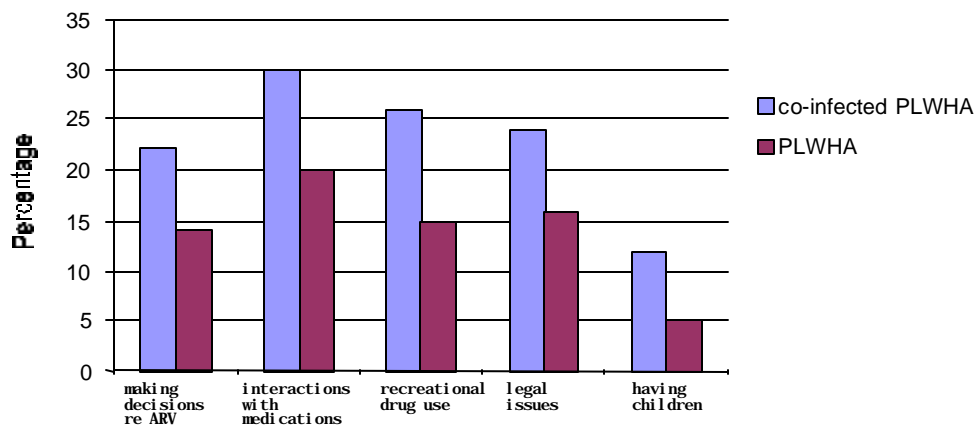
**Table 3** Percentage of co-infected PLWHA that rate the following sources of information as important for treatment and living with HIV/AIDS

| Information source                 | Source of information about: |                      |
|------------------------------------|------------------------------|----------------------|
|                                    | Treatments                   | Living with HIV/AIDS |
| Doctor specialising in HIV         | 90                           | 48                   |
| Other doctor                       | 16                           | 13                   |
| Nurse                              | 27                           | 22                   |
| Pharmacist                         | 23                           | 11                   |
| Alternative therapist              | 28                           | 33                   |
| Treatments officer                 | 35                           | 18                   |
| Other HIV/AIDS organisation staff  | 39                           | 44                   |
| Positive women's organisation      | 10                           | 13                   |
| Injecting drug user's organisation | 12                           | 18                   |
| Haemophilia Foundation             | 9                            | 8                    |
| HIV positive friends               | 47                           | 60                   |
| Other friends                      | 9                            | 17                   |
| Partner/lover                      | 13                           | 27                   |
| Family                             | 11                           | 15                   |
| Gay press                          | 48                           | 46                   |
| HIV magazine/newspaper             | 71                           | 62                   |
| Internet                           | 22                           | 17                   |

In two separate questions, respondents were then asked to report the source of information they considered the single *most* important both in making decisions about *treatments*, and the source of information they considered to be the single *most* important in making decisions about *living with HIV/AIDS*. Doctors specialising in HIV are also most commonly cited (63%) as the *most* important source of information about treatments, however this proportion was significantly lower than that reported by non-co-infected PLWHA (77%). HIV/AIDS organisation staff are most commonly cited (25%) as the *most* important source of information on living with HIV/AIDS.

We asked respondents whether they thought lack of information made it difficult to make decisions about various issues surrounding living with HIV. Co-infected respondents most feel a lack of information when making decisions on interactions between antiretrovirals and other medication (30%), managing side effects (29%), taking a break from antiretrovirals (27%), recreational (party) drug use (26%), and financial planning (24%).

Despite getting information from a wider range of sources, co-infected PLWHA are significantly more likely than other PLWHA to feel they lack information on the following five issues: when making decisions about using antiretroviral drugs (22% v 14%), interactions between antiretroviral drugs and other medications (30% v 20%), recreational (party) drug use (26% v 15%), legal issues (24% v 16%), and having children (12% v 5%) (Figure 6)



**Figure 6** Issues that co-infected PLWHA were more likely to feel they lacked information on than other PLWHA respondents

The HIV-related publications most read by co-infected respondents are *Positive Living* (55%), gay newspapers (62%), *Talkabout* (55%), the *HIV Herald* (44%), and newsletters from community organisations (42%). Co-infected respondents were significantly more likely than other respondents to read the *National AIDS Bulletin* (30% v 16%), newsletters from community organisations (42% v 26%), *With Complements* (48% v 35%) and *NUAA News* (18% v 3%).

**Social support and social issues**

Ninety-eight percent of co-infected PLWHA know other PLWHA. Respondents were asked to indicate how much of their free time they spend with other HIV positive people. The results in Table 4 (below) show that some co-infected respondents spend no free time with other HIV positive people and just over half spend “some” or “a lot” of time with other HIV positive people. There was

no difference between those diagnosed with hepatitis C and those not in terms of the amount of free time they spend with other HIV positive people. Two out of five (39%) co-infected respondents have been involved in the care or nursing of another PLWHA within the last two years - a significantly higher proportion than that reported by other respondents (26%).

**Table 4** Amount of free time co-infected PLWHA spent with other HIV positive people

| Amount of free time | Percentage |
|---------------------|------------|
| Some                | 32         |
| A little            | 29         |
| A lot               | 22         |
| None                | 18         |

Respondents were asked to rate the amount of support they received from people with different relationships to them on a scale of 1 ('a lot') to 4 ('none'). Co-infected respondents received the most support from their partners (mean=1.29), their pets (mean=1.52) and their close friends (mean=1.82). There were no significant differences in the ratings of support given to each group between co-infected PLWHA and the rest of the sample.

Items were included in the questionnaire to assess respondents' levels of depression, views of their own body image, and the meaning of HIV in their lives. The results from co-infected respondents can be seen in Table 5 (below). No significant differences were found between co-infected PLWHA and the rest of the sample on these items. By examining responses to items from the Beck Depression Inventory (the first four items in the table) we sought to gauge respondents' tendencies towards depressive symptoms. Among co-infected respondents, 35% agreed or strongly agreed with none of these items, 27% with one item, 18% with two, 18% with three and 4% with all four. Agreement with all four items is suggestive of clinical depression. Thus like other PLWHA, very few co-infected respondents showed signs indicative of clinical depression.

Most co-infected respondents had a positive body image. Over half (59%) of respondents agreed or strongly agreed that they were happy with the way their body looks, while 54% disagreed or strongly disagreed that changes in their bodies due to HIV/AIDS had made them sexually unattractive. Co-infected respondents also have an ambivalent attitude to their HIV. Most (54%) report that their life had become more meaningful since they were diagnosed with HIV, however 46% report that they prefer not to think about HIV even when they are well. These proportions were similar to those reported by other PLWHA.

**Table 5** Co-infected PLWHA responses to mental health items

|  | Percentage     |       |          |                   |
|--|----------------|-------|----------|-------------------|
|  | Strongly agree | Agree | Disagree | Strongly disagree |
| I cry or feel like crying all the time                                     | 3              | 17    | 60       | 20                |
| I don't enjoy things the way I used to                                     | 12             | 46    | 33       | 9                 |
| I have lost interest in other people                                       | 6              | 30    | 49       | 14                |
| I don't feel it's worth going on   | 2              | 14    | 49       | 35                |
| As long as I'm well I prefer not think about HIV/AIDS                      | 10             | 36    | 44       | 9                 |
| Changes in my body due to HIV/AIDS have made me feel sexually unattractive | 9              | 37    | 42       | 12                |
| I am happy with the way my body looks                                      | 14             | 45    | 34       | 7                 |
| Life has become more meaningful since I became HIV positive                | 16             | 38    | 34       | 13                |

### Planning for the future

Respondents were asked to indicate how far into the future they plan when making major decisions about their lives. Table 6 (below) shows the responses given by co-infected respondents. Co-infected respondents were significantly more likely to plan one day at a time than other respondents. One in three (36%) of co-infected PLWHA have changed how far they plan into the future in the last two years, of whom 74% had started planning using a longer time frame.

**Table 6** Time frame use by co-infected PLWHA when planning for the future

| Time frame used        | Percentage |
|------------------------|------------|
| One day at a time      | 31         |
| A few months ahead     | 23         |
| 1 year ahead           | 30         |
| 5 years ahead          | 10         |
| 10 or more years ahead | 6          |

**Recreational drug use**

As stated earlier 48% of co-infected PLWHA reported injecting in the previous 12 months, compared to 9% of the rest of the sample. Table 7 compares the rate of use of non-prescription drugs by co-infected respondents with that of other PLWHA. While there was a smaller proportion of co-infected respondents that drank alcohol than either the general population (AIHW, 1999) or other PLWHA, considerably greater proportions of co-infected PLWHA use other recreational drugs. Co-infected respondents were less likely to use non-injected speed and amyl than the rest of the sample, but were more likely to use cigarettes, injected speed, injected heroin, injected cocaine, marijuana, and both prescribed and non-prescribed methadone. Co-infected respondents who had injected drugs also started doing so at a younger age (mean=22.6 years) than other respondents (mean=27.1 years).

Most co-infected respondents were content with the amount of drugs they used. Sixty-three percent either disagreed or strongly disagreed with the statement that they use more illegal drugs than they would like. However, co-infected PLWHA were more likely than PLWHA not diagnosed with hepatitis C to report taking more illegal drugs than they would like (37% v 16%). Seventy-seven percent of co-infected PLWHA disagreed or strongly disagreed that they drink more alcohol than they would like. Comparing co-infected PLWHA who had ever taken antiretrovirals to other PLWHA who had ever taken antiretrovirals, revealed that co-infected individuals were more likely to report that they had missed a dose of antiretrovirals due to the use of illicit drugs (36% v 20%). This is not surprising given the greater numbers of co-infected PLWHA who reported using illicit drugs recreationally.

**Table 7** Use of non-prescription drugs in the last 12 months by co-infection status (expressed as a percentage)

|                            | Co-infected PLWHA | PLWHA |
|----------------------------|-------------------|-------|
| Marijuana                  | 76.0              | 51.6  |
| Cigarettes                 | 73.1              | 50.6  |
| Alcohol                    | 72.3              | 84.3  |
| Heroin (injected)          | 33.7              | 2.8   |
| Amyl                       | 31.2              | 40.8  |
| Speed (injected)           | 28.5              | 7.1   |
| Ecstasy                    | 20.3              | 23.3  |
| Cocaine (injected)         | 10.6              | 1.7   |
| Speed (not injected)       | 10.1              | 19.3  |
| LSD/trips                  | 9.8               | 13.0  |
| Cocaine (not injected)     | 8.1               | 8.0   |
| Methadone (non-prescribed) | 4.7               | 2.0   |
| Steroids (injected)        | 3.8               | 5.8   |
| Heroin (not injected)      | 3.0               | 0.7   |

### Housing

The majority (77%) of co-infected respondents live in a capital city, while 15% live in a regional centre or town, and 9% live in a rural area. These proportions are similar to those reported by the rest of the sample.

Table 8 (below) shows the type of accommodation that co-infected respondents currently live in. Co-infected PLWHA were significantly less likely to own or be purchasing their own house or flat, and significantly more likely to live in public rental accommodation or community housing/housing cooperatives. The vast majority (78%) of co-infected respondents believe that their current housing is suitable for their needs.

**Table 8** Current accommodation for co-infected PLWHA

| Accommodation Type                  | Percentage |
|-------------------------------------|------------|
| Own or purchasing own house or flat | 17         |
| Private rental accommodation        | 32         |
| Public rental accommodation         | 30         |
| Live rent-free                      | 6          |
| Community housing                   | 8          |

Among those who felt their accommodation to be unsuitable, the most common reasons were that it is too small (42%), inadequate facilities for carers (36%), and harassment (30%). Inadequate facilities for carers was a more common complaint among co-infected PLWHA who were dissatisfied with their accommodation than among other dissatisfied PLWHA. Sixty-one percent of co-infected PLWHA have changed their accommodation due to having HIV/AIDS – a significantly higher proportion than that reported by the rest of the sample. Among these, the most common reasons for change were moving closer to health services (49% of co-infected PLWHA who moved due to HIV/AIDS), moving to a quieter location (39%), needing cheaper housing (37%), illness (36%), having stopped working (33%), and to avoid harassment (30%). Needing cheaper housing, moving closer to health services, illness, and avoiding harassment were all more common reasons for moving for co-infected respondents than for the rest of the sample.

When asked whom they lived with, 46% of co-infected PLWHA reported that they live alone, 32% live with a sexual partner, 17% live with friends or housemates, 9% live with dependent children, and 7% live with other family members.

### Sexual Relationships

Respondents were asked to describe their sexual orientation or sexual identity. Sixty-one percent of co-infected respondents were homosexual men, 6% were lesbians, 14% heterosexual men, 6% heterosexual women, 12% bisexual men and 1% bisexual women. Co-infected PLWHA were less likely than other respondents to be homosexual men, and were more likely to be heterosexual or bisexual men.

In terms of their current sexual relationships, 29% of co-infected respondents have sex in a monogamous regular relationship, 24% are not currently sexually active, while 21% only have casual sex, 15% have sex in a non-monogamous regular relationship, and 2% are in a regular relationship with more than one person.

Forty-two percent of co-infected respondents who have a regular relationship are in an HIV seroconcordant relationship - the remainder (58%) are in relationships with HIV seronegative partners, or a partner whose serostatus is unknown. All of the respondents who are in regular relationships have told their partner that they are HIV positive. Respondents were asked to indicate when they told their partner that they were HIV positive. Respondents most commonly told their partner when they found out (36%) or stated that their partner already knew they were HIV positive when they started the relationship (20%). Of the remainder, 71% told their partner at the start of the relationship. Respondents were also asked how their partner reacted when they told them that they are HIV positive. Many respondents (59%) said that it did not make any difference. Almost two-thirds (64%) of respondents reported that their partner was very supportive, and 28% said that they became closer, while 29% said that their partner was worried or scared and 8% said that their partner was angry.

When asked about their patterns of condom use during sex with regular partners in the six months prior to completing the survey, 43% of co-infected respondents reported that they always used a condom, 21% reported that they sometimes used a condom, and 36% reported that they never used a condom. These proportions are similar to those reported by other PLWHA. Co-infected respondents were more likely to use condoms with an HIV negative partner than with an HIV positive partner.

When asked about their patterns of condom use during sex with casual partners in the six months prior to completing the survey, 58% of co-infected respondents reported that they always used a condom, 31% reported that they sometimes used a condom, and 12% never used a condom. These proportions are similar to those reported by other PLWHA. Small numbers meant that it was not possible to analyse the relationship between casual partner serostatus and consistency of condom use for the co-infected respondents.

### **Disclosure and discrimination**

Only three respondents (2%) who were infected with both hepatitis C and HIV have not disclosed their HIV status to anyone. Three-quarters (76%) have had their HIV status disclosed when they didn't want it to be – a significantly higher proportion than that reported by other respondents (57%). Co-infected respondents were significantly more likely to report being discriminated against at work at some time due to their HIV status than other PLWHA (31% v 19%).

### **Employment**

Two-thirds (67%) of co-infected respondents were not in paid employment at the time of completing the survey – significantly fewer than the 47% reported by the rest of the sample (see Figure 7 below). Of those that were working, 52% work full-time and 48% work part-time. Co-infected PLWHA more commonly report that being HIV positive has affected their career (90% v 81%). Forty-seven percent of all co-infected PLWHA report that they stopped work due to HIV, 25% report

that it is more difficult to plan, 20% report that having a career is no longer as important, 12% have changed careers since diagnosis and 3% report they are now less likely to change their career. Co-infected respondents were more likely to report that they have stopped work since their HIV diagnosis. When asked the effect of antiretrovirals on their work plans 29% said they haven't changed, 22% that they stopped work, 19% that they haven't used antiretrovirals and 13% that they considered returning to work. Co-infected respondents were more likely to report that antiretrovirals had caused them to stop work (22% v 12%), and less likely to report that they had caused them to return to work (1% v 7%).

Seventy percent of co-infected who have ever worked have stopped doing so at some stage due to their HIV diagnosis – a significantly greater proportion than that reported by other PLWHA (58%). These co-infected PLWHA stopped work for a longer period of time than other respondents (mean=4 years 9 months v mean=3 years 6 months). The last time they stopped working the most common reasons were stress/depression (75%), poor health (59%) and low energy (68%). Significantly more co-infected respondents reported stress/depression as the reason they stopped working. When asked their HIV status at the time they stopped work 46% reported they were HIV positive but had not been ill, 44% they were HIV positive and had been ill, and 10% that they had been diagnosed with an AIDS defining illness. These proportions are similar to those for other respondents. When they were not working 79% received government benefits. Less than half (42%) of these PLWHA have returned to work. The most common reasons for returning to work were financial (71%), better physical health (50%), better psychological health (49%), the desire to do something worthwhile (49%), and the possibility of working part time (48%).

The 33% of co-infected PLWHA who were presently working, work an average of 29 hours per week. Forty-two percent report that their job involves a 'high' or 'very high' stress level. Co-infected workers were more likely than other PLWHA to not be trying to keep their HIV status confidential (50% v 31%).

Sixty percent of co-infected PLWHA who were working reported that their capacity to perform their work duties is affected by having HIV/AIDS. These respondents most commonly report that they tire quickly (70%), work fewer hours (39%), or have difficulty concentrating (58%). Eighty-two percent of workers reported that they could 'often' or 'always' get time off work for medical appointments, 60% for counselling, 85% for sick leave, and 28% for volunteer work.

Co-infected PLWHA were more likely to report that they were considering changing their work arrangements (53% v 40%). Of those who want to change their work arrangements: 57% want to start or return to work, 55% want to change the type of work they do, 21% want to increase their hours, 12% want to reduce their hours. None of the co-infected respondents wanted to stop work. Most of the co-infected PLWHA who want to change their work arrangements perceived that this would be difficult: 31% believe it will be 'very difficult', 62% believe that it will be 'somewhat difficult' and 7% that it will be 'not at all' difficult.

### Finances and poverty

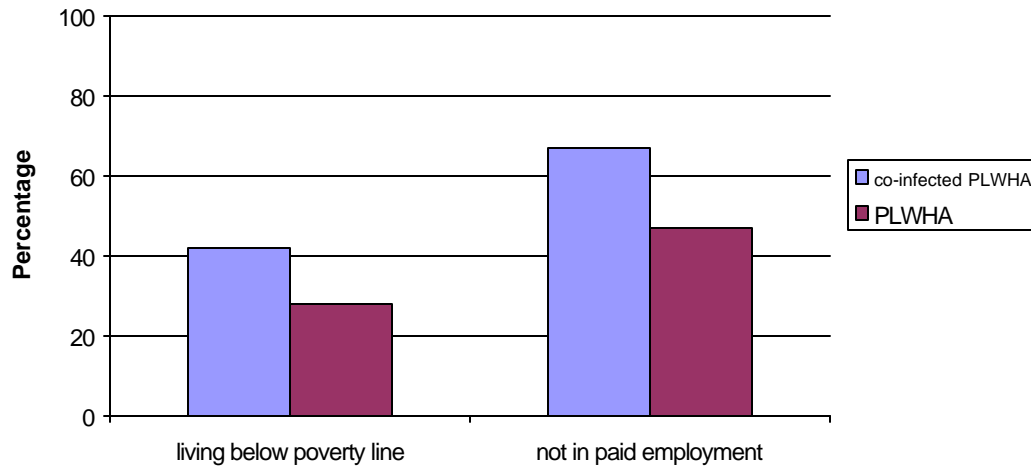
Given the large number of co-infected respondents who are not in paid employment, it is not surprising that these respondents are more likely to report that their main source of income is a government benefit, pension, or social security payment (71% v 49%). Co-infected respondents were also less likely to report having a salary (24% v 40%) or superannuation/annuity/savings (1% v 9%) as their main source of income. Co-infected respondents' incomes (mean=\$286.99/wk) were significantly lower than those reported by other respondents (mean=\$380.51/wk). Furthermore, the average income of the partners of those co-infected respondents who have partners with whom they share financial resources is significantly lower than that for other respondents (\$282.09/wk v \$460.77/wk). Respondents' incomes are displayed in Table 9 (below).

**Table 9** Income reported by co-infected PLWHA

| Weekly income | Yearly income     | Percentage |
|---------------|-------------------|------------|
| \$0 - \$150   | \$0 - \$7800      | 9          |
| \$151 - \$270 | \$7801 - \$14040  | 59         |
| \$271 - \$390 | \$14041 - \$20280 | 9          |
| \$391 - \$510 | \$20281 - \$26520 | 12         |
| \$511 - \$630 | \$26521 - \$32760 | 9          |
| \$631 - \$750 | \$32761 - \$39000 | 1          |
| \$751 -       | \$39001 -         | 1          |

Co-infected respondents were less likely to have private health insurance (7% v 22%), less likely to own or be paying off their own home or flat (20% v 42%), and were less likely to have owned their own house or flat in the past (23% v 42%). They also spent less money per week on rent (mean=\$79.34 v mean=\$104.56).

The poverty lines published by the Institute for Applied Economics and Social Research [IAESR] take into account an individual's income as well as whether or not they are in a relationship and the number of dependent children they have. The data for the September quarter of 1999 (IAESR, 1999) were used to calculate the proportion of PLWHA with incomes below the poverty threshold. Among co-infected PLWHA, 42% reported incomes below the poverty line. This figure is significantly larger than the 28% found for the rest of the sample.



**Figure 7** Poverty and paid employment by co-infection status

Respondents were asked a series of questions that assessed how difficult it is for them to meet the costs of living with HIV/AIDS. The results in Table 10 (below) demonstrate that while many co-infected PLWHA reported difficulties in meeting the costs of social activities such as entertainment and going out, a large proportion reported that it is very difficult for them to meet the costs of some of the “basics” of life such as housing, utilities, food, and clothing.

Particularly noteworthy is the finding that almost a quarter of co-infected respondents find it “very difficult” to meet the cost of food, and that over a third find it “very difficult” to meet the cost of utilities (telephone, gas, electricity). It is also interesting that over a third of the respondents who use complementary/alternative therapies find it very difficult to meet the cost of this treatment. Co-infected PLWHA report significantly more difficulty than other PLWHA in meeting the costs of alternative therapies, entertainment, going out, sport, recreational drugs, travel/holidays, utilities, food, clothing and transport.

**Table 10** Difficulties meeting the cost of living reported by co-infected PLWHA (expressed as a proportion of respondents who use each item)

| Item                               | Percentage    |                    |                |
|------------------------------------|---------------|--------------------|----------------|
|                                    | Not difficult | A little difficult | Very difficult |
| Co-payment for medication for AIDS | 56            | 33                 | 10             |
| Other prescribed medication        | 45            | 45                 | 10             |
| Medical services                   | 49            | 27                 | 24             |
| Complementary therapies            | 30            | 35                 | 35             |
| Support services                   | 74            | 20                 | 6              |
| Entertainment                      | 19            | 31                 | 50             |
| Going out                          | 18            | 27                 | 55             |
| Sport                              | 31            | 33                 | 37             |
| Recreational drugs                 | 18            | 31                 | 51             |
| Travel / holidays                  | 12            | 21                 | 67             |
| Rent / mortgage / housing          | 40            | 41                 | 19             |
| Utilities (phone, gas, etc.)       | 17            | 49                 | 35             |
| Food                               | 31            | 47                 | 23             |
| Clothing                           | 23            | 33                 | 44             |
| Transport                          | 33            | 49                 | 18             |
| Child care                         | 33            | 30                 | 38             |



## **CONCLUDING REMARKS**

The National HIV strategy notes that one of the challenges in providing HIV/AIDS related health promotion for PLWHA is maintaining and increasing our knowledge of opportunistic infections, sexual health, and co-infection with other chronic illnesses (CDHAC 2000a: 21). Similarly the National Hepatitis C strategy notes that co-infection with other blood borne viruses such as HIV and hepatitis B is likely to add to the complex health maintenance needs of those living with hepatitis C and may also expose them to increased stigma (CDHAC 2000b:52). To date, we have very little information on the health and wellbeing of those who are co-infected with both HIV and hepatitis C.

This report provides the first overview of the social and health aspects of living with HIV when co-infected with hepatitis C for a national sample of Australians. Its focus is on aspects of people's experiences of living with HIV. This report does not attempt to explore the social and clinical aspects of managing life with hepatitis C for PLWHA, although the Living with HIV Program at ARCSHS plan further studies.

This report demonstrates that while many aspects of living with HIV are shared regardless of one's hepatitis C status, there appear to be some issues that are likely to affect co-infected PLWHA more than their peers. These findings have important implications for both responses by community organisations (both HIV specific and hepatitis specific) and for those involved in clinical and health management.

The findings of this analysis of data from the HIV Futures II survey, suggest that we need to increase our understandings of not just the impact of one virus on another, but also the synergistic effects - both clinically and socially of living with both viruses.



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