A complex uncertainty

Women on health, hope and living with HIV in Australia

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I think initially [with treatments] there was the sort of feeling of hopefulness and yes, we've got the cure and things changed from a certainty - there was a certain death to more of a complex uncertainty. Because yes, it was good now but – huge buts in there for a lot of people and for me too. But I suppose now that that uncertainty has just been changed to in limbo. It's like well I'm in limbo as it's working now and I'm getting older and I'm in a really stable, happy relationship. This is really good now. Yes, I can think about the future.

Patricia, 45, diagnosed 1985

I think that as each year goes by my hope for the future doesn't change. But I think that the issues and means that arise are becoming more complex not just for me, but for all positive people I think around decision making for treatments and other options that may be available, around work and that sort of thing. I think that that's the only thing that seems to have changed, the complexity of things to think about. I think sometimes when you don't know how long you'll be around it's quite simple really. You focus on just the day to day things and things that make you happy. But, you know, thinking about living a life that you know you could be around for any length of time. Just the complexity of life is huge.

Janelle, 32, diagnosed 1991

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ACRONYMS USED IN THIS REPORT

AFAO	Australian Federation of AIDS Organisations
AIDS	Acquired Immune Deficiency Syndrome
AIHW	Australian Institute of Health and Welfare
ARCSHS	Australian Research Centre in Sex, Health and Society
ARV	Antiretroviral therapy
HIV	Human Immune-deficiency Virus
IAESR	Institute of Applied Economics and Social Research
NAPWA	National Association of People Living With HIV/AIDS
NCHSR	National Centre in HIV Social Research
NCHECR	National Centre in HIV Epidemiology and Clinical Research
PLWHA	People living with HIV/AIDS

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This is the second report on women from the Living with HIV program at La Trobe University. *Standing on shifting sand: Women living with HIV/AIDS in Australia* (1998) Karalyn McDonald, Michael Bartos, Richard de Visser, Doug Ezzy,and Doreen Rosenthal, was the first report examining the social lives of women with HIV/AIDS in Australia. Both of these reports arose out of the original HIV Futures Study conducted in 1997 and we would like to acknowledge the researchers on that project, Doug Ezzy, Richard de Visser, Michael Bartos, Karalyn McDonald, Darryl O'Donnell and Doreen Rosenthal.

EXECUTIVE SUMMARY

Health Status and Health Management

The vast majority of women regularly monitor their CD4/T-cell counts and their viral loads. The results of women's most recent tests indicate that 50% have a viral load below the level of detection, and that 39% have CD4/T-cell counts indicative of little damage to their immune system. However, 15% have a high viral load and a CD4/T-cell count indicative of severe immune system damage.

Two-thirds of women reported good or excellent health. However, 19.8% have been diagnosed with an AIDS-defining illness, 29.8% have experienced other AIDS-related illnesses, and 43.1% have a major health condition in addition to HIV/AIDS. Many women also reported experience of lipodystrophy, weight loss, sleep disorder, or memory loss and confusion. The current health status of women and men was very similar.

Nearly all women have had a Pap smear. Many of these women have had more than one Pap smear in the previous year. Most women reported that the results of their Pap smears were clear, however, 24.7% reported an abnormal Pap smear result.

Use of Antiretroviral therapy

Fewer than two-thirds (59.8%) of women use antiretroviral drugs. Women are significantly less likely than men to use ARV drugs and significantly less likely than men to have ever used ARVs. The majority of women using ARV drugs take three or more drugs in combination.

Many women reported difficulties taking ARV drugs: 53.6% reported side-effects; 52.3% have difficulty remembering to take drugs on time; and 26.9% have difficulty taking a large number of tablets. Despite these difficulties, most women are compliant with their treatment regimens: 76% reported that they did not miss a dose of their ARV drugs in the two days prior to completing the survey.

Most women reported that both their physical health and their sense of well-being have improved while using ARV drugs. However, many women are concerned that their medication may stop working in the future.

All but one of the women not currently using ARV drugs said that they would consider using such treatments in the future, especially if their health deteriorated.

Although many women expressed favourable attitudes toward ARV drugs, a large proportion expressed uncertainty about the safety and efficacy of ARV drugs. Men were significantly more likely than women to believe that *Antiretroviral drugs mean better prospects for most people.*

Women were significantly more likely than men to use complementary therapies.

Well-being and Information

Women use of various health services is related to whether the focus was general medical care or HIV-specific treatment. Women tend to see HIV specialists or Doctors working in the HIV/AIDS field for their HIV-related care, but are more likely to consult generalist GPs for non-HIV care.

Many women must go to two or more places to obtain their prescription medication. These women were significantly more likely to report that it is difficult to obtain their HIV medication.

Nearly half of the women reported an experience of HIV-related discrimination at medical services. Women were significantly more likely than men to report that they have experienced less favourable treatment at a medical service as a result of having HIV.

Women reported that a Doctor specialising in HIV is their most important source of information about treatments for HIV/AIDS. However, their most important source of information about living with HIV/AIDS is Positive Women's Organisations.

Many women reported that they lack information about many aspects of living with HIV/AIDS, particularly interactions between ARV drugs and other medication, taking breaks from treatment, and managing side-effects of ARV drugs.

The most frequently read HIV/AIDS related publication was the nationally distributed newspaper *Positive Living*. However, many women read newsletters and information from community organisations.

The vast majority of women have contact with an HIV/AIDS organisation, most know other HIV positive people, and most have disclosed their HIV status to partners, friends, and/or family. However, few women spend a lot of their free time with other HIV positive people.

Although most women indicated that their HIV status is an important part of their self-concept, few women said that their HIV status is an essential part of their identity. More important than HIV were gender, sexuality, and parenthood.

Most women identified at least one person in their life as a source of a lot of social support. However, there was wide variation between women in the number of people who give them a lot of social support. Women listed parents, partner/spouse, close friends and pets as sources of social support.

A small but significant number of women expressed attitudes indicative of psychological distress. Use of anti-depressive medication was significantly more likely among women whose attitudes indicated greater psychological distress.

Many women appear to be more optimistic about the future. In the past two years many women have changed the timeframe they use when planning for the future, and frequently women have changed to using a longer timeframe. Most commonly such a change was due to improved health.

Women and children

Half of the women surveyed have dependent children. A number of these women gave birth to their children after being diagnosed with HIV. More than half of the women with children have told their children aged 18 or younger that they have HIV.

A small proportion of women have either decided to have children in the future or are currently trying to become pregnant. However, the vast majority of women are not considering pregnancy and childbirth in the future.

Sex and Relationships

Half of the women reported that they are in a regular relationship or married. It is interesting to note, however, that 41.4% of women are not currently sexually active. One-third of women in a regular relationship have a partner who is also HIV positive. Use of condoms with regular partners was related to the partner's HIV serostatus, such that women whose regular partner is HIV negative are significantly more likely to always use condoms, whereas few women with HIV positive regular partners always use condoms.

A small proportion of women had sex with a casual partner in the 6 months prior to completing the survey. The majority of these women always used condoms during sex with casual partners.

Many women appear unsure of the impact of HIV on forming new relationships, and the impact of HIV on sexual pleasure. Few women agree that new treatments make safe sex less important, or that they feel more confident about unprotected sex because of the new treatments.

Recreational Drug Use

Rates of recreational drug use among HIV positive women appear to be similar to those found in the general population. However, HIV positive women are significantly less likely than HIV positive men to use recreational drugs. Few women reported that they have experienced bad interactions between ARV drugs and recreational drugs, or that using illegal drugs has caused them to miss a dose of ARV drugs. Few women feel that they use alcohol or other drugs more than they would like to.

Two-thirds of women have never injected illegal drugs, but 11.9% indicated that they had injected illegal drugs in the 12 months prior to completing the survey. One of these 10 women reported that she shared needles in this time period and that the person with whom she shared needles with was also HIV positive and Hepatitis C positive.

Accommodation

Three quarters of women find their accommodation unsuitable for their needs, most commonly because it is too small, too expensive, or too far from services. A substantial minority of women have changed their accommodation as a result of HIV/AIDS. The most commonly cited reasons for changing accommodation were to move closer to health services and to find cheaper accommodation.

Employment

Fewer than half of the women who completed the survey are in paid employment and most of those who are employed work part-time.

Although nearly all women indicated that being diagnosed with HIV affected their career plans (eg stopping work or changing careers), fewer than half indicated that combination ARV therapy has affected their career plans.

Half of the women indicated that at some time they have stopped work for reasons related to their HIV diagnosis. Fewer than half of these women subsequently returned to work. Those who returned to work did so because of better physical health, better psychological health, or financial necessity.

Around half of the women in paid employment reported that their work capacity is reduced by HIV/AIDS because they tire more quickly, have to work reduced hours, or have difficulty concentrating. Most of the women in paid employment reported that their employer gives them flexibility to take time off when they are sick or to attend medical appointments, however, they had less flexibility to take time off for counselling.

Finances

More than half of the women who completed the survey report that their major source of income is a government benefit and one-third receive their income from a salary. It is important to note that 45.7% of women reported an income below the poverty line, and that the majority of women dependent on a government benefit live in poverty. Women were significantly more likely than men to report an income below the poverty line. However, women who shared their financial resources with a partner or spouse were significantly less likely to live in poverty than women who did not.

Many women report difficulty meeting their costs of living. The items most commonly reported as being difficult to afford related to social activities. However, a substantial proportion of women report that it is very difficult for them to pay for clothing, food, and utilities such as gas and electricity.

INTRODUCTION

This report is the second from the Living with HIV program that specifically addresses the status of women with HIV/AIDS in Australia. The report comes, as did its predecessor *Standing on Shifting Sand,* from a national survey of Australian PLWHA. The HIV Futures II survey is a core component of a broader program of research concerned with the social and psychological experience of living with HIV. The HIV Futures surveys bring together the clinical, social and personal experiences of living with HIV in recognition of the fact that living with HIV is not solely an experience of illness. The survey gathers information on health and treatment, accommodation, social support, mental health, use of services, sex and relationships, recreational drug use and community involvement.

This report aims to further our understanding of the status of women living with HIV in Australia. In doing so it recognises that the experience of living with HIV for women differs in some fundamental ways from that of both homosexual and heterosexual men. Issues like visibility, disclosure, discrimination, child rearing and relationships often have a different importance and meaning for positive women. Within a culture where the majority of PLWHA are gay men, there has been a particular need for HIV positive women to balance the need for visibility within the positive community and recognition of the particular needs of women, with the possibility of discrimination and the burden of responsibility that comes with such visibility.

Globally, at the end of the twentieth century, it was estimated that there were 33.6 million people living with HIV/AIDS (WHO, 1999). Of HIV positive adults 46% are women. In order to understand the forces that shape the health and well-being of people with HIV it is critical to appreciate the role of social and economic inequality and disadvantage that operates at all levels of society. Poverty, discrimination, access to the means of prevention, health maintenance and treatment, social isolation, religious and political cultural practices all play a part in determining the health possibilities for PLWHA.

In order to understand the health and well-being of women with HIV it is critical to appreciate how these inequalities and disadvantages operate at the level of gender. At a global level, women continue to have less access to economic and social independence, fewer resources and fewer options for the maximisation of their health generally, and their sexual health specifically. These factors operate differently within different social and political contexts, but the commonalities represent a collective experience that reminds us of our responsibilities within the international community.

At a national level it is important to recognise the differences in the history of the epidemic for women and men. There has been an ongoing struggle to maintain the visibility of HIV positive women, to ensure that treatments are appropriate for women and that women's health issues are adequately researched, and to ensure that education and support services reach and are appropriate for women. It is also important to appreciate the advances that have been made in the visibility and representation of, and service provision to, HIV positive women in Australia. The contribution of positive women's organisations to this advancement cannot be overemphasised.

At a community level we must recognise the differences in the social and geographical communities in which many positive women live. These differences have important implications for issues like disclosure, social support and community participation. This is not to suggest that women with HIV are isolated or disenfranchised from broader positive community.

At an individual level we must recognise that the collective experience of HIV and the differences between various populations of PLWHA is mediated by the lives of individuals, each unique and complex.

This report gives an overview of the lives of Australian women with HIV at the end of the twentieth century, in a world where advances in treatments have changed the landscape for people with HIV. These changes may have brought greater hope, but they have also brought greater complexity; they may have brought greater optimism, but they have also brought greater uncertainty.

INSTRUMENT AND METHOD

The Survey Instrument

The HIV Futures II survey was an anonymous, self-complete, mail back questionnaire consisting of 193 items organised into eight sections: demographics; accommodation; health and treatments; services and organisations; sex and relationships; employment; recreational drug use; and finances. Each section included an explanation of the purpose of the items. Most items in the survey were closed-coded with either single or multiple response options. *Other* categories were included for most items to ensure that significant experiences of living with HIV were not excluded. There were a number of attitude/ belief items scored using a four and five point Likert scales. There were also write-in and open-ended items.

The survey, once completed, was returned in a reply-paid envelope to the Living with HIV program. In addition participants were given the option, via a separate mail-back, of adding their contact details to the program mailing list to receive reports and to participate in further research.

The instrument was based in large part on the original HIV Futures survey (Ezzy et al., 1998) with most items retained in their original format to allow comparisons between the two studies. Additional sections and items were included to reflect the changes in both the personal experiences of living with HIV/AIDS, and the changes in policy and service context in the past two years.

A series of community consultations with organisations and individuals around the country was conducted prior to the development of the instrument. Particular attention was paid to the strengths and weaknesses of the original survey, and to the changes that had been observed in the intervening period. A community reference group with members drawn from State and national AIDS and PLWHA organisations was established early in the development of the instrument. This group ensured that the instrument was appropriate in language, style and focus. The group also provided feedback on the meaning and implication of the findings prior to the preparation of this report.

A copy of the survey instrument is available for perusal on the website:
www.latrobe.edu.au/hiv-futures/

Recruitment

As the broad aim of this study was to represent the collective and individual experiences of people with HIV/AIDS in Australia, a purposive, multi-faceted community sampling strategy was employed. Participants were recruited using a multi-pronged approach including mail-out, organisational distribution, and advertisement. Participants from the original HIV Futures study mailing list were sent two copies of the survey and were asked to pass the second copy onto anyone they knew who may not have received a copy. Advertisements inviting PLWHA to participate in the study were placed in HIV/AIDS, gay and lesbian and injecting drug use publications. Press releases were issued to both mainstream and community press promoting the launch of the study. A website was established where PLWHA could either request a copy of the survey or download one. Central to the recruitment strategy was the involvement of community organisations who distributed copies of the surveys to their members and promoted the surveys in their publications. Copies of the survey were mailed out in issues of *Talkabout, Positive Life* and *QPP Alive.*

Active recruitment took place between August and October 1999, although a small number of surveys were returned during November and early December and these were included in the analysis.

In order to allow for meaningful comparisons between specific populations of PLWHA, it was necessary to target recruitment to ensure over-sampling of marginalised groups. These populations included women, people with Haemophilia, those living outside NSW and Victorian metropolitan areas and injecting drug users.

Sample Demographics

The survey was completed by 89 women out of a total of 924 respondents: 828 of the remainder were men, three respondents were transgender and four respondents did not indicate their gender. The whole sample represents approximately 8% of the current population of people living with HIV/AIDS in Australia as estimated by the *Australian HIV Surveillance Report* (NCHECR, 1999). The 89 women represent 10% of the total estimated number of women living with HIV/AIDS in Australia.

Female respondents’ ages ranged from 18 to 62 years with a mean of 38.2 years and a median age of 36 years. Women’s ages at the time of diagnosis ranged from 18 years to 64 years (mean = 31.6 years, median =30.0 years). The average length of time since women first tested positive was 6.7 years. More than half (51.8%) of the women have been positive for between five years and ten years, 28.9% have been positive for less than five years and 18.1% have been positive for more than ten years.

Of the 89 women who completed the survey, 82.9% identified as heterosexual, 11.4% identified as lesbian or gay and 5.7% identified as bisexual. Only one woman did not indicate her sexual orientation.

In order to compare the sample of women to the population represented in the Australian HIV Surveillance Reports, participants were asked how they believe they were infected with HIV. The results, grouped by the categories used by the National Centre in HIV Epidemiology and Clinical Research[1] [NCHECR] are given below in Table 1.

Table 1: Women's reported mode of transmission

Mode of Transmission	Frequency	Percentage
Heterosexual contact (sex with a man)	58	66.7
Injecting drug use	14	16.1
Receipt of blood components/tissue	13	14.9
Other	2	2.3

N=87

The distribution of mode of transmission differs from that in 1997. In 1999 no women indicated the categories: injecting and heterosexual contact; or sex with a woman. Two women did not indicate how they believe they were infected with HIV.

Slightly more than one half (50.6%) of female respondents said they have dependent children. Almost one third (32.3%) have one dependent child, 13.8% have two dependent children, one woman (1.1%) has three dependent children and another woman (1.1%) has four dependent children.

Generally, women reported high levels of education. One quarter (24.4%) have a university degree and 23.3% have a tertiary diploma. One fifth (19.8%) have completed secondary education, a further 30.2% have completed some secondary education and 2.3% have completed primary education.

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[1] Source: National Centre in HIV Epidemiology and Clinical Research (NCHECR) (1999) Australian HIV Surveillance Report 15(4).

The majority of female participants were Australian born (76.7%) and 97.7% of women speak English at home, with European languages accounting for the remainder. Four women (4.5%) indicated they are of Aboriginal/Torres Straight Island origin.

Women came from all Australian states and territories, with the majority coming from NSW, Victoria and Queensland (see Table 2).

Table 2: State or Territory of women's residence

State/Territory	Frequency	Percent of sample
NSW	29	33.0
Vic	23	26.1
Qld	11	12.5
WA	15	17.1
SA	6	6.8
Tas	2	2.3
ACT	1	1.1
NT	1	1.1

N=88

The majority (48.9%) of women were from inner urban areas of capital cities, while 22.7% live in outer suburban areas, 20.5% live in larger regional centres and 8.0% live in rural areas.

Most women (84.3%) live in the same state or territory in which they were infected with HIV, while the remainder have moved to Australia from overseas or now live in a different state or territory.

Around one third (33.0%) of women indicated that they are atheist/agnostic, 47.6% indicated mainstream religious identification and the remainder are either adherents of new age belief systems or had other spiritual beliefs. Over one quarter (28.2%) indicated that religion or spirituality was of no importance to them. A further 29.4% indicated that this is of little importance, 29.4% that it is very important and 12.9% extremely important.

Weighting of the Sample

In order to ensure that the results reported in this document accurately represent the Australian population of PLWHA, comparisons were made to the Australian HIV Surveillance Report (NCHECR, 1999) and the data was weighted to conform with the demographic profile of the Surveillance Report. Because we deliberately over-sampled marginalised populations, the sample under-represents gay men from NSW and over-represents women, heterosexual men, those from non-metropolitan areas and those outside NSW. A weighting algorithm based on mode of infection, gender, state of residence and diagnosis of AIDS defining illness has been applied to all the analyses that follow. Consequently, findings are generally presented in terms of sample percentages rather than frequencies, except where numbers are very small. These Ns are weighted. Statistical comparisons including ANOVA and chi-square have been employed in the analysis of the data, although for clarity the details of these are not included in this report. All significant differences reported have a probability of at most $\alpha=0.05$.

I was tested one week and they said it would take a couple of days. And I rang up and they said 'yes it's here, the results are in'. Went in, I waited two hours before they showed me into the doctor and she said 'I haven't got the results'. That was on the Thursday and on the Friday the nurse rang me at work and I said 'are you sure?' and she said 'definitely'. I went in and I waited I think another hour. Imagine what it was like? And all the time she would ignore me, she was a bitch. And when the doctor told me on the Thursday "oh, I don't have the results', I just walked out. She was going 'hang on a minute'. I just -- I walked out. And then on the Friday I waited another hour in the surgery. She said 'well I've got your results'. And at this stage I had convinced myself I was okay, because [my ex-partner's] other partner that he'd had after me, she'd had her results and she was clear. So I'd convinced myself that I'm fine, you know, not a problem… there was no understanding, no compassion. Keeping me waiting all that time. I can't even look at that lady in the eye again now.

Allison, 38, diagnosed 1996

HEALTH

The first half of this report is concerned with the physical health of people with HIV/AIDS. Here we are not concerned just with the clinical indicators of health (CD4 counts and viral load), but with the experience of health. We have asked about general sense of physical well-being, about side-effects and changes in people's bodies. There is considerable emphasis on the uptake of, and taking of antiretroviral therapy, as this has been one of the dominant themes in any discussion of living with HIV in the past few years. But again, not simply in terms of the treatments themselves, but how they fit (or don't fit) into peoples lives, what changes they have made to people's quality of life (both positive and negative) and what it means to take them. We have also looked at health management including complementary therapies, an important part of many PLWHA's lives.

HEALTH STATUS

Summary:

The vast majority of women regularly monitor their CD4/T-cell counts and their viral loads. The results of women’s most recent tests indicate that 50% have a viral load below the level of detection, and that 39% have CD4/T-cell counts indicative of little damage to their immune system. However, 15% have a high viral load and a CD4/T-cell count indicative of severe immune system damage.

Two-thirds of women reported good or excellent health. However, 19.8% have been diagnosed with an AIDS-defining illness, 29.8% have experienced other AIDS-related illnesses, and 43.1% have a major health condition in addition to HIV/AIDS. Many women also reported experience of lipodystrophy, weight loss, sleep disorder, or memory loss and confusion. The current health status of women and men was very similar.

Nearly all women have had a Pap smear. Many of these women have had more than one Pap smear in the previous year. Most women reported that the results of their Pap smears were clear, however, 24.7% reported an abnormal Pap smear result.

CD4/T-cells and Viral Load

As with the 1997 survey, nearly all women had taken a CD4/T-cell test (98.8%) and a viral load test (97.7%). Most women had their most recent CD4/T-cell test within the last six months

(96.2%) and their most recent viral load test within the last six months (97.2%). On average women had taken four viral load tests in the preceding twelve months.

Among women who have taken a CD4/T-cell test, 87.4% reported that they have at some time had a CD4/T-cell count of less then 500 cells/μL and 62.2% reporting a count of less than 250 cells/μL. Results for women’s most recent CD4/T-cell test ranged from 0 to 900 cells/μL (mean of 422.0 cells/μL, median of 456.6 cells/μL) while men’s most recent CD4/T-cell test ranged from 0 to 1300 cells/μL (mean of 499.4 cells/μL, median of 460.0 cells/μL).

Among women who have taken a viral load test, 75.3% reported that at some point they have had a result of over 10,000 copies/μL and 51.2% a result of over 50,000 copies/μL. Results of women’s most recent viral load test ranged from below detectable levels to 2,000,000 copies/μL (mean of 132,115.3 copies/μL, median of 795.8 copies/μL) while men’s most recent viral load test ranged from 0 to 14,000,000 copies/μL (mean of 59,147.1.0 copies/μL, median of 500.0 copies/μL). It is important to note that at the time of the survey viral load assays of differing sensitivity were being used. It is possible that some respondents who reported an undetectable viral load may have had a measurable (though low) level if a more sensitive assay had been used.

Table 3 shows the combined CD4 and viral load results of the sample. The results are grouped by three levels of CD4 count: little damage, moderate damage and severe damage, and four levels of viral load: below detectable levels, low, moderate and high. As different assays would have been used to assess the respondent's viral loads we have defined *below detectable levels* as being those responses that were less than 500 copies/μL and those where the respondent wrote in *zero* or *below detectable level*. One quarter (26.4%) of women reported a viral load below the level of detection and a CD4/T-cell count indicative of little damage to their immune system. However, 15.3% reported a high viral load and a CD4/T-cell count indicative of severe damage to their immune system. The serological profiles of these women indicate that HIV is making a severe impact on their immune system.

Table 3: Results of most recent serological tests, percentage of all women

			Viral load			
			Below detectable levels	Low 500 to 9,999	Moderate 10,000 to 49,999	High 50,000+
			50.0	19.4	7.0	23.6
CD4/T-cell	Little damage 500+	38.9	26.4	11.1	1.4	0.0
	Moderate damage 250-499	30.5	15.3	5.5	1.4	8.3
	Severe damage 0-249	30.6	8.3	2.8	4.2	15.3

N=72

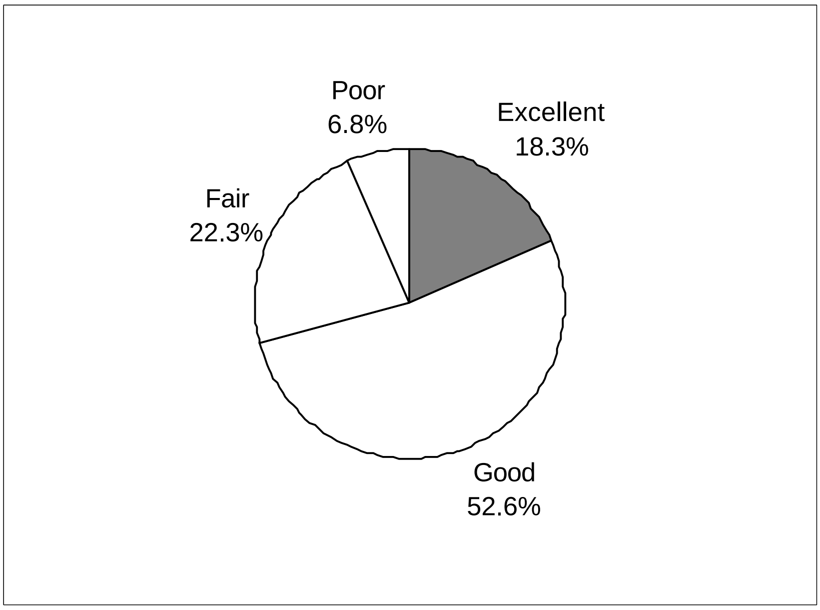
Two women have not had a CD4/T-cell test and one woman has not had a viral load test. The reason given by all women was that they believe they do not need to take these tests.

One in five (19.8%) women have been diagnosed with an AIDS defining illness at some point. They were most likely to have received this diagnosis in 1997 (29.4%) with a further 10.5% having received such a diagnosis in 1999. The most commonly reported AIDS defining illnesses were Pneumocystis carinii pneumonia (PCP; seven women), Mycobacterium avium complex (MAC; five women), Oesophageal Candidiasis (three women), Cytomegalovirus (CMV: three women) and cervical cancer (three women). Women were no more or less likely than men to be diagnosed with an AIDS defining illness.

Experience of Health

Respondents were asked to rate their current state of physical health on a four-point scale. The majority of women rated their general health as *good* (52.6%), while only 6.8% rated their health as *poor* (see Figure 1). Women with an AIDS defining illness were significantly more likely to rate their health as *poor* or *fair* than were those who did not have an AIDS defining illness.

Figure 1: Women's self ratings of general health status



N=87

HIV/AIDS Related Conditions

One in three women (29.5%) reported that they have experienced HIV related illnesses. Most commonly, women reported experiencing fungal infections (19.3%), wasting or weight loss (17.9%) and Oral Candidiasis (16.7%). Respondents were also specifically asked about a number of conditions that have been identified as being of concern among PLWHA. One quarter (24.8%) of women reported that they have experienced Lipodystrophy, 29.7% have experienced weight loss, 35.3% have had a sleep disorder, and 31.8% have experienced confusion or memory loss.

Other Health Conditions

More than one third (43.1%) of women reported that they have at least one major health condition other than HIV/AIDS. Of the women who reported other major health conditions the most common was hepatitis C (37.6%), followed by cardiovascular disease (13.5%), cancer (8.0%) and hypertension (7.2%).

Hepatitis

Few women have had hepatitis A (9.4%) or hepatitis B (10.5%). Two thirds (66.8%) of women have been tested for hepatitis C, and of these 37.1% tested positive. Because women most at risk of Hepatitis C virus infection are more likely to have been tested, it is likely that the proportion of women coinfected with Hepatitis C virus is less than 37.1%.

Pap Smear tests and GART

Almost all (97.0%) of the women surveyed have had a Pap smear. Of those women who said they had had a Pap smear, 45.8% had taken one Pap smear in the 12 months before the survey, 30.4% had taken two Pap smears, and 7.2% had taken three.

Of the women who reported their most recent test result in this survey 75.3% had come back clear and 14.9% abnormal. In addition, one woman (1.5%) reported low-grade intraepithelial abnormality (cervical intraepithelial neoplasia 1 - CIN1). Five women (6.9%) reported high-grade intraepithelial abnormality (one woman reported CIN2 and four women reported CIN3). One woman (1.4%) said her test results were inconclusive. These results are consistent with the Victorian Cervical Cytology Registry which in May 1998 reported 14.4% of women in Victoria had abnormal smears.

Of the women who have not had a Pap smear test two women have had a hysterectomy, one woman said she has not been advised to have a Pap smear and another woman said she has not gotten around to it.

Genotypic antiretroviral testing (GART) is a relatively new technique that assesses drug resistance. As an indication of the degree of health monitoring in this population, 18.3% of women reported that they have taken a GART.

Health Maintenance

When asked to identify the things women do to improve their health, the most commonly reported activities were: sleep (68.5%); having a good diet (64.9%); relaxation (60.0%); taking medication at the right time (58.3%); exercise (62.0%); complementary therapies (48.9%); and spending time with pets (41.5%). Other activities included spending time with partner/friends or family, spending time with children, and reading or studying.

Prophylaxis

One third of women (33.3%) use prophylactic medication for conditions like PCP. Women using prophylaxis were significantly more likely than other women have been diagnosed with an AIDS defining illness (66.7% versus 24.6%). In the Futures I sample women were significantly less likely than men to be using prophylaxis for opportunistic infections (men 37.5%; women 56.3%). However, there was no significant difference between women and men in use of prophylaxis in the Futures II sample (men 33.1%; women 33.3%)

Attitudes to Health Management

Participants responded to a number of statements about health management, antiretroviral treatment and complementary therapies. Almost all women agree with the statement *looking after my physical fitness is an important part of managing my HIV infection.* Similarly, almost all women agree with the statement *keeping an optimistic frame of mind is an important part of managing my HIV infection* (see Table 4).

Table 4: Attitudes to health management: percentage of all women

	Strongly Disagree	Disagree	Agree	Strongly agree
Looking after my physical fitness is an important part of managing my HIV infection	0.0	3.3	49.8	46.9
Keeping an optimistic frame of mind is an important part of managing my HIV infection	1.3	3.6	39.4	55.7

N=84.

> *…but now you sort of go to the clinic and one thing I don't like about it is, that you sort of imagine … like you go into the hospital feeling a million dollars, you have a great day, you go in and get your test results and they're not so good, you come out and you're feeling terrible. So you are measured when you take these drugs, you know, your viral load, your blood count, rather than the whole, you know, 'well how are you doing?'. It's sort of like the drugs are doing the work, so all things are fine… I could do without the monthly visits to the clinic, to the hospital… but it's a constant reminder when you have to take all the pills each day, you can't ever get away from it.*
>
> *Sharon, 39, diagnosed 1990*

ANTIRETROVIRAL THERAPY

Summary:

Fewer than two-thirds (59.8%) of women use antiretroviral drugs. Women are significantly less likely than men to use ARV drugs and significantly less likely than men to have ever used ARVs. The majority of women using ARV drugs take three or more drugs in combination.

Many women reported difficulties taking ARV drugs: 53.6% reported side-effects; 52.3% have difficulty remembering to take drugs on time; and 26.9% have difficulty taking a large number of tablets. Despite these difficulties, most women are compliant with their treatment regimens: 76% reported that they did not miss a dose of their ARV drugs in the two days prior to completing the survey.

Most women reported that both their physical health and their sense of well-being have improved while using ARV drugs. However, many women are concerned that their medication may stop working in the future.

All but one of the women not currently using ARV drugs said that they would consider using such treatments in the future, especially if their health deteriorated.

Although many women expressed favourable attitudes toward ARV drugs, a large proportion expressed uncertainty about the safety and efficacy of ARV drugs. Men were significantly more likely than women to believe that *Antiretroviral drugs mean better prospects for most people.*

Women were significantly more likely than men to use complementary therapies.

Use of Antiretroviral Therapy

At the time of the 1997 survey antiretroviral therapy in triple combination and with protease inhibitors was relatively new and one key concern of that survey was on the uptake of these drugs. Since 1997, the relationship of PLWHA to antiretroviral drugs has become more complex. People have experienced a range of difficulties in taking the drugs, from problems with drug toxicity, side effects and iatrogenic illness, the development of drug resistance to problems with dosing and compliance. New drugs have been developed and recommendations about combinations, dosage and monitoring have changed as more data has become available. The issue of structured interruptions to treatments, including drug holidays and pulse therapy, has received considerable attention. There are now PLWHA who have very different experiences of antiretroviral therapy, from those who have only ever used one combination of drugs, to those who have changed combinations frequently, to those who have taken breaks at various times, to those who have never used any of these treatments. In order to adequately reflect this diversity of experience, in 1999 we asked a more comprehensive range of questions about treatment history, with a particular emphasis on the past two years.

Respondents were asked if they are currently using or had used a range of antiretroviral therapies. On the basis of their answers to these items, they were asked further questions on their experiences of antiretrovirals (ARVs).

Slightly less than two thirds (59.8%) of women were currently using ARVs at the time of the survey. However, 75.9% said they had used ARVs at some point in the past. For men, 75.2% were currently using ARVs and 87.7% had used them in the past. Almost three quarters (73.6%) of all respondents were currently using these treatments and 86.5% had used ARVs at some point. As in 1997, women are significantly less likely than men to be currently using ARVs (see Table 5). Women are also significantly less likely than men to have ever used ARVs.

Table 5: Use of antiretrovirals by gender and year

		Women	**Men**
1997 Using ARV[1]			
	Yes	61.5%	79.2%
	No	38.5%	20.8%
1999 Using ARV[2]			
	Yes	59.8%	75.2%
	No	40.2%	24.8%

1:N=888 2:949

The data on treatments will be presented in four sections: those women currently using ARVs (mono-therapy and combination therapy); those women currently on combination therapy only; those women not currently using ARVs who have in the past; and those women who have never used ARVs. A summary diagram of women's uptake of antiretrovirals can be found on page 36.

Women using ARVs (mono-therapy and combination therapy)

Of the women currently using antiretroviral therapies, half (46.9%) use a combination of 3 drugs[2], a further 16.7% use 4 or more drugs, 33.8% use 2 drugs and 2.8% are on mono-therapy (one woman). The specific drugs being used are listed in Table 6 below.

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[2] In this analysis, Combivir, which is a combined dose of AZT and 3TC is counted as two drugs.

Table 6: Antiretroviral drugs used by respondents: percentage of all women

Drug	% of women using ARV
d4T	32.4
3TC	27.6
ddI	15.5
Nevirapine	14.8
Nelfinavir	12.7
AZT & 3TC (Combivir)	11.4
Saquinavir-soft gel	11.0
Efavirenz	6.3
Indinavir	6.1
Indinavir	6.1
1592	5.7
Ritonavir	3.7
Saquinavir-hard gel	3.4
AZT	3.3
ddC	2.8
Delavirdine	3.3
Adefovir	0.9
Loviride	0.0

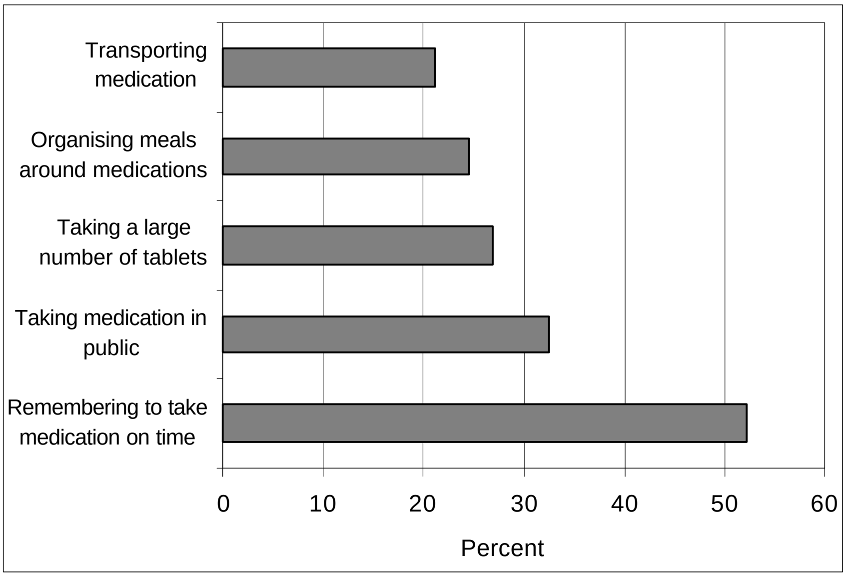
N=51 (Multiple responses possible)

Respondents were also asked specifically about their use of the immune stimulants Interleukin-2 and Hydroxyurea. One woman was using Hydroxyurea and no women were using Interleukin-2.

Difficulties of Taking ARV

Overall, 83.0% of women reported that they have difficulty taking ARVs (see Figure 2). Of those women using ARV, many have difficulty: remembering to take the drugs on time (52.3%), taking medication in public (32.4%), taking a large number of tablets (26.9%), organising meals around medications (24.6%) and transporting medication (21.1%). In addition, 13.4% (seven women) reported that taking ARVs makes it difficult to take medication for other health conditions and 7.3% (four women) reported that taking other medication makes taking ARVs difficult. Women were no more or less likely than men to experience difficulties taking ARV.

Figure 2: Difficulties for women taking ARV



N=53

Most women (61.9%) take ARVs twice per day, while 31.7% take ARV three times a day and 6.3% were taking these medication 4 or more times per day.

When participants were asked how many doses of ARV they had missed in either of the two days before completing the survey, 76.3% of women reported missing no doses, 20.0% missed one dose, and two women (3.7%) missed two or more doses. Women were no more or less likely than men to miss doses of ARV in either of the two days before completing the survey.

Side effects were reported by 53.6% of women using ARV. The most commonly reported problems were diarrhoea (25.0% of those using ARV), nausea (21.2%), Lipodystrophy, vomiting, insomnia, skin rashes or irritation, and neuropathy (7.8% respectively) and headaches (5.8%). There were no significant differences between women and men in the side effects they reported.

Attitudes

Almost two thirds of women reported concern over the future efficacy of their treatments (See Table 7). Many women agree with the statement *I am worried that in the future my medication will stop working for me*. In addition, many women agree with the statement *Taking tablets gives me an unwanted reminder that I have HIV*.

Table 7: Attitudes to medication: percentage of those women using ARV

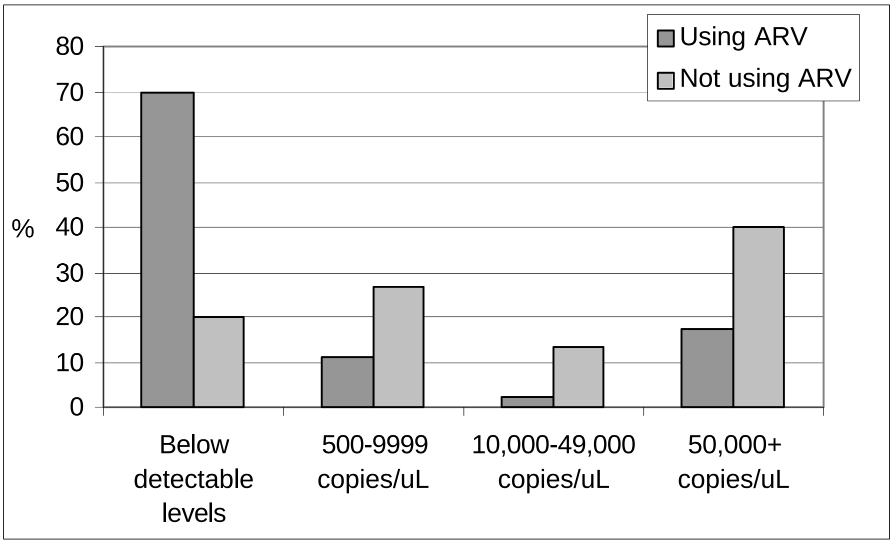
	Strongly Disagree	Disagree	Agree	Strongly agree	Don't know
I am worried that my medication will stop working for me [1]	3.3	15.0	45.3	20.5	15.9
Taking tablets gives me an unwanted reminder that I have HIV [2]	9.8	33.0	37.5	17.9	1.8

1: N=52, 2: N=52

Health Status of Women Using ARV

Women taking ARV were significantly more likely to report an undetectable viral load (up to 500 copies/µL) than women not taking ARV (69.6% versus 20.0%; Figure 3). Conversely, women not taking ARV were significantly more likely to report a viral load of 50,000 copies/µL or more than those women taking ARV (40.0% versus 17.4%). Women taking ARVs did not have significantly different CD4/T-cell counts to women not taking ARV. There were no differences between women taking ARV and not taking ARV in how they rated their current physical health.

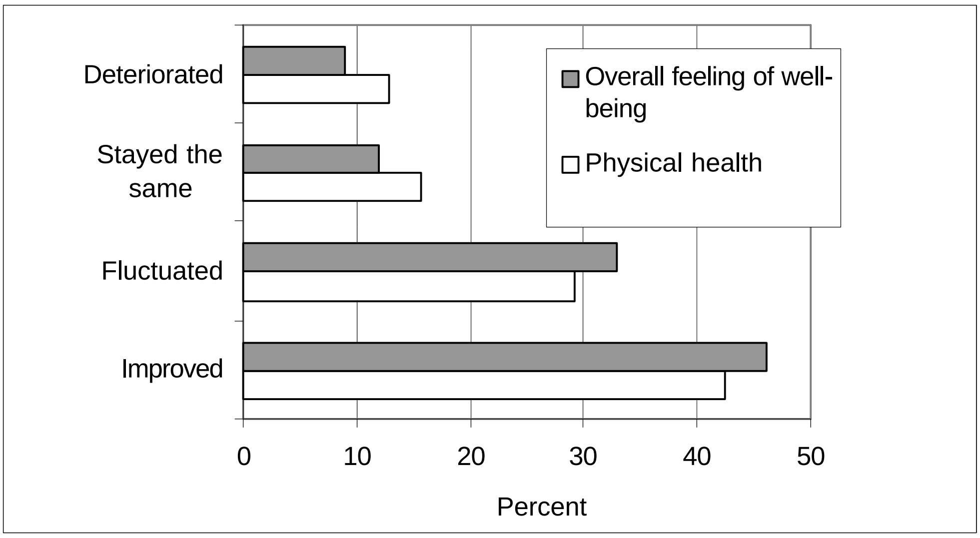
Figure 3: Viral loads for women taking and not taking antiretroviral therapy.



N=46 (using ARV) N=30 (not using ARV)

When asked to rate the effect of commencing ARV on their physical health, 42.5% of women said that their health improved, 29.2% said it fluctuated, 15.6% said it stayed the same and 12.8% said it deteriorated. When asked about the impact of ARVs on their overall feeling of well-being, 46.1% said it had improved, 33.0% said it had fluctuated,11.9% said it had stayed the same and 9.0% said it had deteriorated (see Figure 4).

Figure 4: Effect of commencing antiretroviral medication on health of women



N=52 (well-being) N=52 (physical health)

Respondents were asked if they had taken a break from ARV therapy at any time in the past. More than half of the women had not taken any breaks (58.8%). Of those that had taken a break (41.2%), the most commonly cited reason was that side effects became too severe (59.1%). Drug resistance was cited by 45.5% as the reason they had a break from treatment, while 31.8% said they had taken a break from treatment to clean out their system and 31.8% said they had taken a break to have a drug holiday[3]. Problems with compliance were reported by 13.6% of women as a reason for taking a break from treatment.

Respondents were specifically asked if they were undertaking pulse therapy, which involves cycles of treatment followed by non-treatment as a therapeutic technique. Only three women currently on ARV therapy said they were currently undertaking pulse therapy.

Women using Combination Therapy

As noted earlier, almost all women using ARV were on some form of combination therapy. The most common combination was D4T, Nelfinavir and Loviride, which was used by five women. Four women were using ddC, Nelfinavir and Delaviride. Three women were using ddC and Efavirenz and a further three women were using Nelfinavir, Delaviride and Loviride. Either two women or one woman reported the remaining combinations.

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[3] The proportion of women taking breaks who indicated a structured break for either a drug holiday or to clean out the system was 45.2%

Men using antiretroviral combinations (n=648) were most likely to report being on combinations of ddC, Nelfinavir and Loviride (9.0%), ddC, Nelfinavir and Delaviride (6.2%), Saquinavir (Invirase), Nelfinivir and Loviride (5.4%) and d4T, Nelfinavir and Loviride (4.9%).

Most women started combination therapy at a time when their viral load was high (mean =561,797.8 copies/µL) and their CD4/T-cell count was low (mean = 195.9, 61.6% below 250 cells/µL, 92.2% below 500 cells/µL). Although the number of women who recalled the results of their last viral load test before they commenced combination therapy is small (23), women on average, do have higher viral loads before commencing combination therapy than do men (women's mean viral load =561,797.8 copies/µL; men's mean viral load=325,873.4 copies/µL). This indicates that women are waiting longer before commencing combination therapy. Of those women who could recall their viral load and CD4/T-cell count before they commenced combination therapy, most women had commenced therapy at a time when treatment would be strongly advised (see AFAO, 1997). See Table 8.

Table 8: Results of women's serological tests prior to ARV commencement.

			Viral load prior to commencing combination therapy (%)			
			Below detectable levels	Low 500 to 9,999	Moderate 10,000 to 49,999	High 50,000+
			13.0	8.7	34.8	43.5
CD4/T-cell prior to commencing combination therapy (%)	Little damage 500+	60.9	13.0	0.0	17.4	30.4
	Moderate damage 250-499	26.1	0.0	8.7	8.7	8.7
	Severe damage 0-249	13.0	0.0	0.0	8.7	4.4

N=23

When asked about the circumstances surrounding their commencement of combination therapy, women were most likely to indicate that they were advised to do so by their doctor, although the importance of clinical indicators and treatment information is also clear (Table 9).

Table 9: Circumstances surrounding commencement of treatment among women using combination ARV.

Circumstance	Percentage of women using combination therapy
My doctor advised me to begin this treatment	81.2
I had a big drop in my CD4 count	55.9
New drugs became available	34.2
I became very ill	30.6
Information showed the treatment was effective	25.7
I had a big rise in my viral load	16.9
I was hospitalised due to HIV	12.8
Close friends advised me to begin treatment	10.2
My partner advised me to begin treatment	10.2
A treatments officer advised me to begin treatment	6.8
I became pregnant	6.0
Positive friends started treatment	2.6

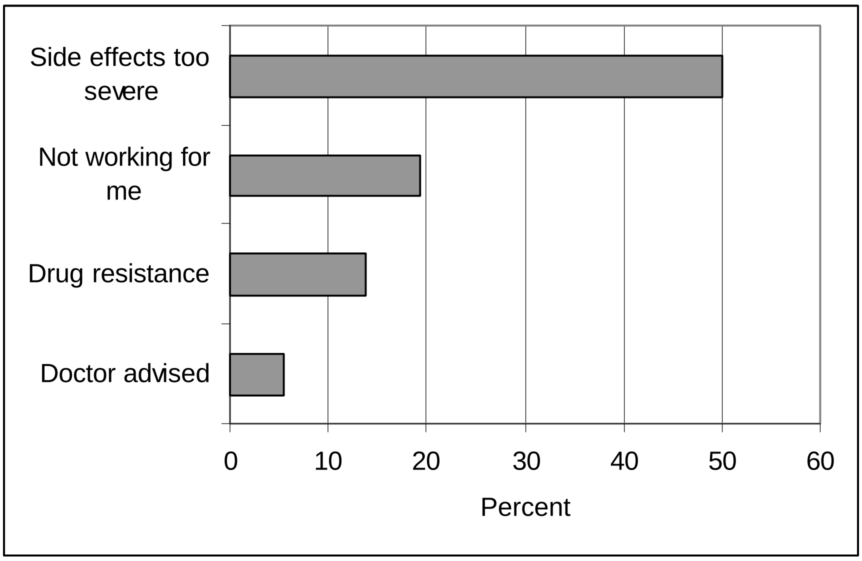
N=50 (Multiple responses possible)

Different Combinations

Most women had used between one and four different combinations of drugs. One fifth (19.3%) had used one combination, 22.8% had used two, 18.7% had used three, and 18.6% had used four combinations of ARVs during their entire treatment. Within the last 12 months, 60.0% of women had used the one combination and 18.7% had used two. There were no significant differences between men and women in the number of drug combinations they have used.

Respondents currently on combination ARV were asked to describe the circumstances surrounding their most recent change in combination. For half of the women (50.0%) the side effects became too severe (see Figure 5). The next most commonly cited reasons for changing combinations were that the drugs were not working (19.4%); that drug resistance developed (13.8%); or that the respondent’s doctor advised the change (5.5%).

Figure 5: Circumstance surrounding most recent change in combination among women currently on combination ARV



N=46

Participants taking combination therapy were asked how many combinations they believe they have access to. The majority of women (53.5%) think they have *many* combinations available, 34.9% feel they have *a few*, two women (4.7%) said they have only one combination remaining, and three women (6.9%) said they have no combinations remaining.

Women Not Currently Taking ARV

Of the 40.5% of women not using ARVs, 40.9% have done so in the past. The mean length of time women used ARVs was 2.4 years (range 1 month to 7 years) and on average they had ceased using ARVs 2 years and 2 months prior to completing the survey (range 1 month to 7.5 years). At the time that they stopped using ARVs, most women were using a combination of three drugs (68.8%), 5.9% were using four drugs, 9.1% were using two drugs and 1.9% were on mono-therapy.

Difficulties Taking ARV

The pattern of difficulties experienced by women who have stopped antiretroviral therapy and women currently taking antiretrovirals differs considerably, as can be seen from Table 10. Of the 14 women who have previously used ARVs, but are not currently taking ARVs, the vast majority (82.0%) reported that they had some difficulty taking ARVs. These respondents reported difficulty: remembering to take the drugs on time (78.4%), organising meals around medications (53.5%), taking medication in public (40.4%), transporting medication (39.7%), and taking a large number of tablets (37.7%). In addition, 14.6% of women reported that taking

ARVs made it difficult to take medication for other health conditions and 13.5% reported that taking other medication made taking ARVs difficult.

Table 10: Difficulties experienced by women currently on ARV and those who have stopped ARV treatment.

Difficulties experienced	Taking ARV now[1]	Have taken ARV in the past, but not now[2]
Side effects	53.6	93.6
Remembering to take drugs on time	52.3	78.4
Organising meals around medications	24.6	53.5
Taking medication in public	32.4	40.4
Transporting medicine	21.1	39.7
Taking large number of tablets	26.9	37.7
ARV makes taking other medication difficult	13.4	14.6
Other medication makes taking ARV difficult	7.3	13.5

1: N=53, 2: N=13 (Multiple responses possible)

Side effects were reported by 93.6% of women who had used ARVs in the past but were not currently using them. This is significantly more than the proportion of women currently using ARVs. The most commonly reported problems were nausea (60.8% of those reporting side effects), dizziness or blurred vision (33.9%), vomiting (20.0%), diarrhoea (18.7%) and gas or bloating (15.6%),

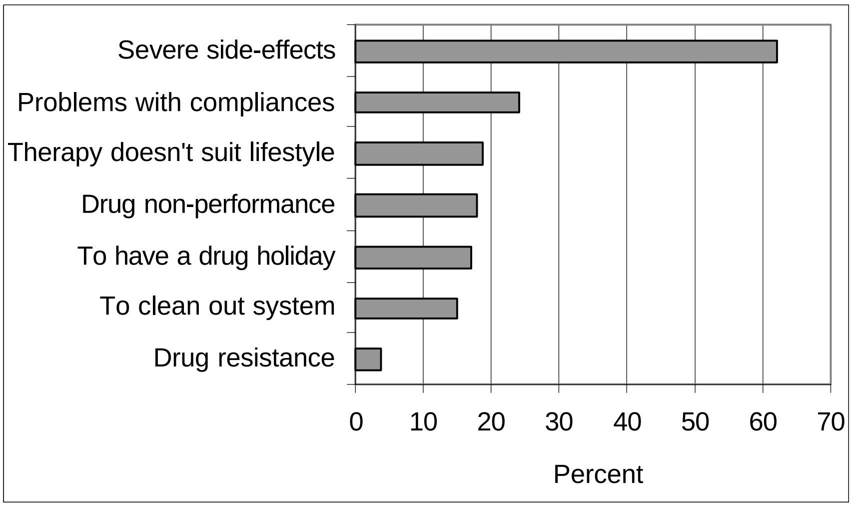
Health Status of Women Not Using ARV

Those not currently using ARV were asked to describe the effect on their physical health when they had used ARV in the past. One third of women (34.8%) said that their health had deteriorated, 24.4% said it fluctuated, and 40.8% said it stayed the same. No women said that their health had improved.

When asked about the impact of ARVs on their overall feeling of well-being, 54.6% of women said it had deteriorated, 30.5% said it had fluctuated and 14.9% said it had stayed the same. No women said their feeling of well-being had improved while they were taking ARV.

Respondents were asked why they had stopped using antiretroviral therapy. The reason most commonly cited by the 13 women was that side effects had become too severe (62.2%). Less than one fifth (15.0% - two women) said they had taken a break from treatment to clean out their system and 17.0% to have a drug holiday.[4] Some women (18.7%) said that the therapy did not suit their lifestyle. Drug resistance was given as a reason by 3.7% and non-performance by 18.0%. Problems with compliance were reported by 24.1% (See Figure 6).

Figure 6: Women's reasons for discontinuing combination ARV: percentage of women not currently on ARV



N=13

Most women had used three (68.8%) combinations of ARVs during their entire treatment, 13.2% had used four, 16.2% had used one and 9.1% had used two combinations.

Women Who Have Never Used Antiretroviral Drugs

More than half (59.1%) of the women who were not currently using antiretroviral drugs said they had never used ARV drugs. Women were significantly more likely than men to report that they have never used ARV drugs (24.1% versus 12.3%).

Considering Antiretroviral Drug Use in the Future

Of the 21 women who had never used ARV drugs, almost all (96.1%) said they would consider using ARV therapy at some point in the future. Similarly, 91.7% of women who had used ARV

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[4] The proportion of those taking breaks that indicated a structured break for either a drug holiday, or to clean out the system was 30.7%

drugs in the past but were not currently using them said they would consider using ARV therapy in the future.

The circumstances in which women would consider using ARV drugs mainly related to health status (see Table 11). The majority of women currently using ARV drugs said that their doctor's advice was an important factor in their decision to start ARV drugs. In contrast, women who are not using ARV drugs appeared less likely to be influenced by the advice of their doctor.

Table 11: Circumstances that would lead to the commencement of antiretroviral therapy among women who are not currently using antiretroviral drugs.

Circumstance	% of those women not on ARV.
If I became very ill	82.0
If I had a big drop in my CD4 count	72.9
If I had a big rise in my viral load	67.1
If I was hospitalised due to HIV	66.1
If my doctor advised me to begin this treatment	47.4
If new drugs became available	38.1
If information showed the treatment was effective	36.0
If a treatments officer advised me to begin treatment	18.4
If my partner advised me to begin treatment	7.9
If close friends advised me to begin treatment	3.7
If positive friends started treatment	0.0

N=32 (Multiple responses possible)

Of the two women who said they would not consider using antiretroviral drugs in the future, one woman said she preferred to pursue palliative care options and the second woman said she did not wish her lifestyle to be restricted by illness potentially caused from ARV.

Attitudes to Antiretroviral Therapy

All participants were asked to respond to a range of statements about antiretroviral drugs. These statements fall into two broad areas: treatment uptake and decision making; and treatment optimism.

Treatment uptake and decision making

More than half of the women disagree with the statement *I am healthy now and don't need to use antiretroviral drugs* (61.2%) (See Table 12). Women who agree with this statement are significantly less likely to be using any ARV drugs (64.7% versus 3.9%). Men were more likely than women to disagree with this statement (73.1% versus 61.2%).

Only a small number of women agree with the statement *Combination antiretroviral drugs are ineffective* (6.0%). They were somewhat more likely to agree that *Combination drugs are harmful* (28.8% agree, 13.8% strongly agree). This may be related to the impact of side effects, as is suggested by responses to the statement *The side effects of antiretroviral drugs outweigh the benefits,* with which 28.8% agree and 13.8% agree strongly, while 19.4% are unsure. Women using ARV were more likely to disagree with this statement than were women who were not using ARV (57.4% versus 25.7%). There were no significant differences between men and women in these attitudinal statements.

As was found in the original 1997 survey, most women (89.6%) agree with the statement *My doctor and I work together to find the best treatment for me*, although in ‘Futures II’ a larger proportion of women support the statement that *My doctor knows more about the treatment of HIV than I do* (64.8% in 1999, 58.0% in 1997). This may reflect the increased complexity of HIV treatment regimens.

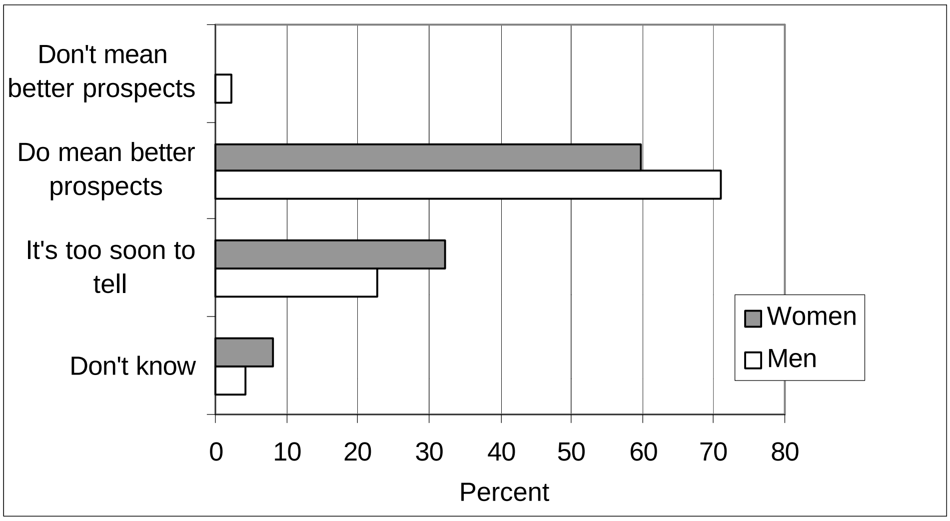
Treatment Optimism

Overall, women are cautiously optimistic about the ability of ARV drugs to improve their lives. Half (52.8%) agree with the statement *Combination antiretroviral drugs have allowed me to plan my life with confidence in the long term*. There was greater uncertainty about the impact of these treatments on life expectancy, with 33.0% indicating that they are unsure whether *HIV treatments will stop me dying from AIDS.* In terms of future treatment developments, almost two thirds (63.4%) of women agree with the statement *New treatments will be developed in time for me to gain benefits.*

Participants were also asked to respond to the statement *Antiretroviral drugs mean better prospects for most people,* both in terms of their own beliefs and those of their friends. Less than two thirds of women (60.0%) agree with the statement, and believe their friends would agree with it (62.9%). This is an increase of 23% over the 1997 survey, mostly with a shift from the *It’s too soon to tell* category to the *agree* category. Almost one third of women believe that *it’s too soon to tell* (32.0%), although they were less likely to think their friends think this (14.8%). Few (8.1%) said they don’t know but many (22.3%) do not know what their friends think. No women said that either themselves or their friends did not believe that ARVs mean better prospects for most people.

As in 1997 there was a significant difference in the way women and men view antiretroviral drugs as better prospects. In both 1997 and 1999 men were more likely than women to believe that *Antiretroviral drugs mean better prospects for most people* (1999 – 70.9% versus 59.8%, 1997 – 58.6% versus 37.2%). (See Figure 7).

Figure 7: Women and men's responses to the statement *Antiretroviral drugs mean better prospects for most people in 1999.*



Women: N=87; Men: N=853.

Table 12: Attitudes to antiretroviral drugs: percentage of all women

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
I am healthy now and don't need to use ARV drugs	23.7	37.5	15.8	12.8	10.2
People with HIV should start using ARV drugs as soon as possible	11.3	28.4	26.3	5.8	28.3
Combination ARV drugs are ineffective	34.2	44.1	4.4	1.6	15.7
Combination ARV drugs are harmful	15.3	23.1	28.3	13.8	19.5
The side effects of ARV drugs outweigh the benefits	5.2	38.6	21.8	8.9	25.5
My doctor and I work together to find the best treatment for me	0.0	6.8	59.4	30.2	3.6
My doctor knows more about the treatment of HIV than I do	4.2	22.5	36.0	28.8	8.5
Combination ARV drugs have allowed me to plan my life with confidence in the long term	6.8	14.3	33.4	19.4	26.1
HIV treatments will stop me dying from AIDS	8.6	12.1	20.6	12.4	46.3
New treatments will be developed in time for me to gain benefits	2.1	1.5	47.1	16.3	33.0

N=77-87 N varies from item to item due to missing data.

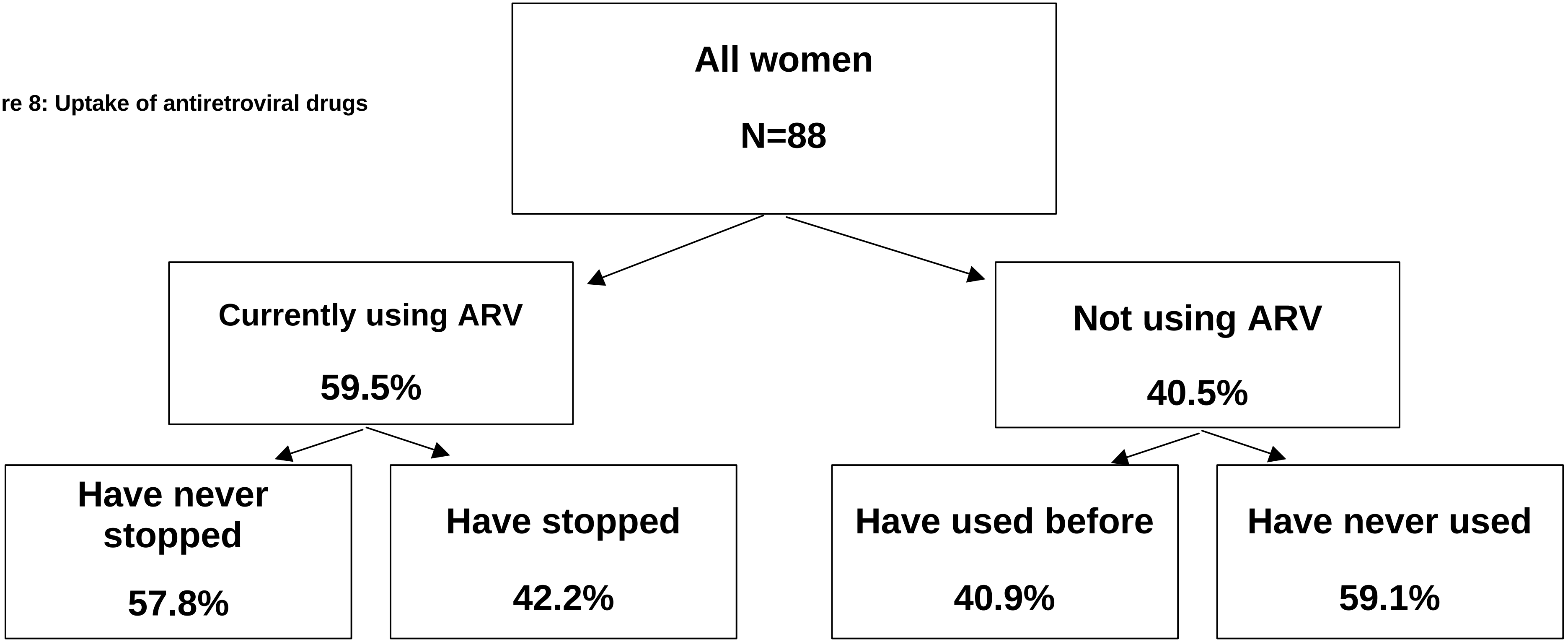


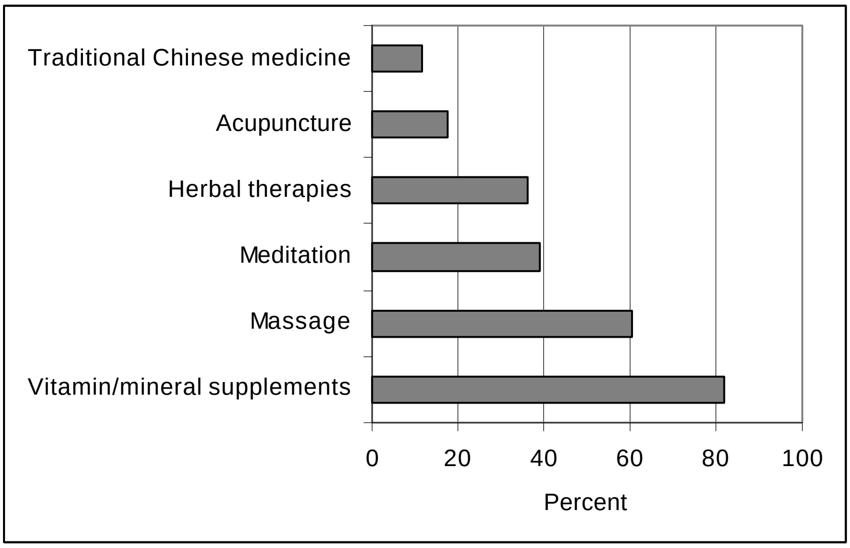
Figure 8: Uptake of antiretroviral drugs

COMPLEMENTARY THERAPIES

More than two thirds (69.0%) of female respondents were using complementary therapies for HIV. Women were significantly more likely than men to be using complementary therapies (69.0% versus 54.0%). Women using complementary therapies spend on average $18.93 per week on complementary therapies. There was no significant difference between men and women who are using complementary therapies in the average amount they spend per week ($18.93 versus $16.17).

The most common complementary therapy was vitamin or mineral supplements (81.7% of women using complementary therapy), followed by massage (60.5%), meditation (39.1%), herbal therapies/supplements (36.1), acupuncture (17.9%) and traditional Chinese medicine (11.7%) (see Figure 9). Women using complementary therapies were no more or less likely than other women to use ARVs.

Figure 9: Complementary therapies most commonly used by women



N=59

Almost all women believe that complementary therapies can improve well-being (see Table 13). Almost two thirds also believe complementary therapies can delay the onset of illness due to HIV, can reduce side effects of conventional medication, and almost three quarters believe complementary therapies can boost the immune system. However, around one third of the women are unsure about these two statements.

Table 13: Attitudes to complementary therapies: percentage of women

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
Complementary therapies can delay the onset of illness due to HIV	0.9	5.5	35.4	26.8	31.4
Complementary therapies can improve well-being	0.0	1.6	42.6	42.8	13.0
Complementary therapies can reduce the side effects of conventional medical treatments	2.3	0.0	41.1	25.0	31.6
There is not enough evidence to be sure about the benefits of complementary therapies	10.5	31.6	36.6	2.7	18.6
Medicine's focus on anti-HIV drugs is very limited	2.4	15.3	39.0	13.9	29.4
Complementary therapies can boost the immune system	2.3	2.9	37.0	35.4	22.4

N=82-86 N varies from item to item due to missing data.

Compared to other women, those who are unsure of the efficacy of complementary therapies are less likely to use complementary therapies. Women were significantly more likely than men to agree: that complementary therapies can delay the onset of illness due to HIV (62.4% versus 48.9%); that complementary therapies can reduce side effects of conventional medical treatments (65.9% versus 49.6%); that medicine's focus on anti-HIV drugs is very limited (53.0% versus 39.7%); and that complementary therapies can boost the immune system (72.6% versus 57.5%).

Because I was very much into complimentary therapy, herbal medicines, I didn't want to have any of these toxic drugs. Then I saw the impact of treatment[s]… and now I look back and see that's what it was. Particularly on women. And I felt that they seemed, you know, and the anecdotal evidence to me was that women seemed to be suffering to a greater extent than men. I was terrified of the side effects. Going on these drugs that I was going to be on for the rest of my life and I thought probably my liver won't last that long.

Miranda, 48, diagnosed 1991

I think that for me treatments did reinforce my positive status, but so I mean that's probably around why the compliance was a bit difficult for me as well. So since I'm not on treatment I feel like that's not being reinforced every day as it was. I think it's a fluid thing, because I know at some point sometimes I feel like it's very much my identity. But I think because I do have other roles in my life that it sort of changes.

Janelle, 32, diagnosed 1991

I'm wary about it because just – I mean I don't mind taking things that are short term, but something as long term, like that really puts me off, health wise. And then I see people and hear lots of stories about side effects, particularly to women. And yeah it scares me. But my health comes first and I want to live a long life. So if that means I have to go that way then I will take treatment.

Narelle, 30, diagnosed 1997

It's given me more time and more energy and more of a life since I started taking [antiretrovirals] -- that's the reason I started taking them … because I was so low that I couldn't go much lower, you know. So I lost a lot of weight and I thought well I have to give it a go and also I wanted to sort of test it out about how it would be for my child. So I started taking them and I felt much better, instantly much better, like within a week, I felt much better.

Carmen, 35, diagnosed 1985

At least now I've been told I can have my break that I decided to give myself, when I had [my baby], I decided not to take any more of the tablets. It was like there were heaps and heaps of them. Like twenty, thirty, forty a day and [it] usually made me sick. All the side effects and I just couldn't cope with it any more. As well as having morning sickness all the time so I thought 'OK as soon as I have her, I'm having a break'. So we had one lot of blood tests come back and then the doctor said he'll work on it for a few weeks with the other doctors and see what they can come up with, what to try me on next, what tablets. And they still don't know.

Maggie, 33, diagnosed 1986

Once you've been on medication for so long you get sick of taking the pills -- but you know that you've got to take them, so 'okay, I'll take all those pills only because I have to'. But to deal with the diarrhoea I have to take another pill to fix that, but I don't want to do that. I'm sick of taking pill after pill and -- I'm doing the DDI twice a day and I went away on a positive women's - people's camp a couple of weeks ago and they had a dietician there who told me 'did you know that DDI, you could take one dose, just in the morning or at night, it doesn't matter, you only have to have the one dose'. And it's like -- ddI's really huge -- you either chew them or you can dissolve them. They don't fully dissolve either, and she said to me 'if you do that as a double dose in the morning then you can take the Immodium [at night]'. So I'm not like, you know, stopping one, cutting down one, or whatever.

Catherine, 31, diagnosed 1990

WELL-BEING

The following section explores the social aspects of positive women’s lives, both those aspects directly related to having HIV, like the use of medical services, and those aspects that, though not directly related to the physical fact of being HIV positive, are nonetheless influenced by the social fact of being positive, such as employment, finances and relationships and family and parenting. We have examined the way in which women interact with AIDS services and community organisations that exist to serve the needs of positive people, and with the *HIV/AIDS community*, in the many ways that that can be defined. There are also sections on the mental health of women, on social support, on recreational drug use, on sources of information about HIV and on the way PLWHA see their future. Our aim with this section is to give a more complete picture of the lives of positive women than is often seen in research of this type, and to relate that to the physical health of women living with HIV/AIDS.

Summary:

Women’ use of various health services is related to whether the focus was general medical care or HIV-specific treatment. Women tend to see HIV specialists or Doctors working in the HIV/AIDS field for their HIV-related care, but are more likely to consult generalist GPs for non-HIV care.

Many women must go to two or more places to obtain their prescription medication. These women were significantly more likely to report that it is difficult to obtain their HIV medication.

Nearly half of the women reported an experience of HIV-related discrimination at medical services. Women were significantly more likely than men to report that they have experienced less favourable treatment at a medical service as a result of having HIV.

Women reported that a Doctor specialising in HIV is their most important source of information about treatments for HIV/AIDS. However, their most important source of information about living with HIV/AIDS is Positive Women’s Organisations.

Many women reported that they lack information about many aspects of living with HIV/AIDS, particularly interactions between ARV drugs and other medication, taking breaks from treatment, and managing side-effects of ARV drugs.

The most frequently read HIV/AIDS related publication was the nationally distributed newspaper *Positive Living*. However, many women read newsletters and information from community organisations.

The vast majority of women have contact with an HIV/AIDS organisation, most know other HIV positive people, and most have disclosed their HIV status to partners, friends, and/or family. However, few women spend a lot of their free time with other HIV positive people.

Although most women indicated that their HIV status is an important part of their self-concept, few women said that their HIV status is an essential part of their identity. More important than HIV were gender, sexuality, and parenthood.

Most women identified at least one person in their life as a source of a lot of social support. However, there was wide variation between women in the number of people who give them a lot of social support. Women listed parents, partner/spouse, close friends and pets as sources of social support.

A small but significant number of women expressed attitudes indicative of psychological distress. Use of anti-depressive medication was significantly more likely among women whose attitudes indicated greater psychological distress.

Many women appear to be more optimistic about the future. In the past two years many women have changed the timeframe they use when planning for the future, and frequently women have changed to using a longer timeframe. Most commonly such a change was due to improved health.

Health Services

Treatment

Respondents were asked about their use of medical services. In order to capture some of the complexity in the ways in which PLWHA use general practice, hospital and community medical services, we asked respondents who they use for general and HIV specialist care, and where they obtain a range of information and services.

For general medical treatment more than one quarter of women (27.1%) see a General Practitioner (GP) who specialises in HIV. While it is often difficult to distinguish what is and what is not HIV related, some women choose to go to a different doctor for day to day care than the doctor they go to for HIV specific treatment. Around one third (31.0%) of women visit a generalist GP for general medical care and 16.1% visit an HIV specialist physician. Women were significantly more likely than men to go to a generalist GP for their main general medical treatment (30.6% versus 18.8%) whereas men were significantly more likely than women to report that they see their GP who specialises in HIV for their main general medical treatment (47.6% versus 27.1%).

For HIV related treatment, 22.1% of women visit a GP who specialises in HIV, 39.9% visit a HIV specialist physician, and a smaller number visit a doctor at an outpatient clinic or a doctor at an AIDS organisation. Women were significantly more likely than men to say they go to an HIV specialist for their main HIV-related treatment (39.8% versus 29.0%) whereas men were significantly more likely than women to report that they see their GP who specialises in HIV for their main HIV-related treatment (40.4% versus 21.6%).

Less than half of the women (42.4%) visit a doctor in a different category for general treatment than they do for HIV specific treatment (See Table 14). One fifth of women (20.2%) visit a doctor in the same postcode area to their residence, as do men (20.9%).

Table 14: Physician used for general and HIV related treatment: percentage of women

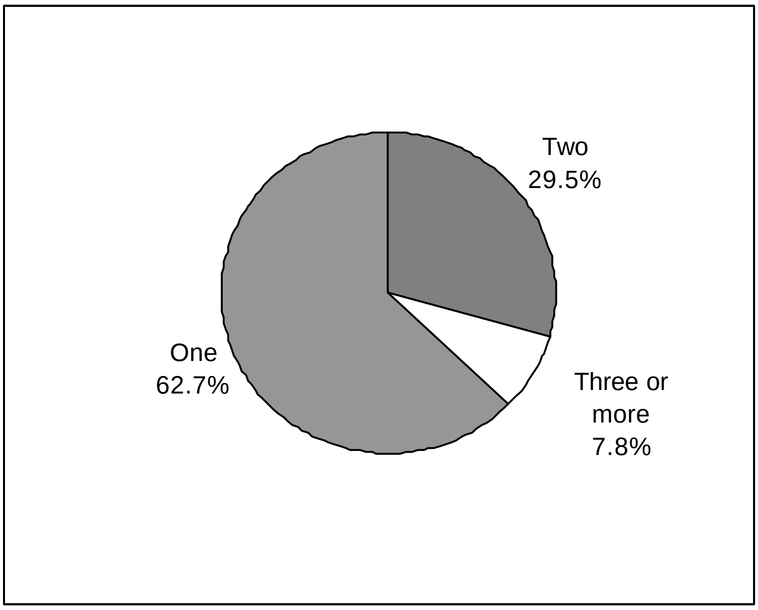
	For general Treatment^1	**For HIV specific Treatment^2**
Generalist GP	31.0	4.1
GP who specialises in HIV	27.1	22.1
HIV specialist/physician	16.1	39.9
Dr. at hospital/ outpatient clinic	11.7	14.3
Dr. at sexual health centre	8.9	13.7
Dr. at HIV/AIDS organisation clinic	4.6	4.4
Dr. at hospital inpatient clinic	0.6	0.0
Other	0.0	1.5

1:N=84; 2:N=88

Prescriptions

Almost one third of the women (29.8%) get their prescriptions for antiretroviral drugs from an HIV specialist. The remainder of the women get their prescriptions from: a GP who specialises in HIV (18.8%); a hospital outpatient clinic (14.8%); a sexual health clinic (12.5%); an HIV/AIDS organisation clinic (4.5%); their generalist GP (1.4%). Slightly more than one third of women said that each prescription lasts one month (39.5%) and a further one third said that it lasts three months (38.0%). For some (19.0%) the prescription lasts two months and for 3.4% it lasts six months. The majority of women go to only one place to pick up all of their prescription medication (62.7%). However, almost one third (29.5%) must go to two places and a small proportion (7.8%) need to go to three or more sites. (See Figure 10).

Figure 10: Number of prescription pick-up points for women



N=64

Women going to two or more places were significantly more likely than those going to one place to indicate that this was difficult (50.0% versus 25.6%) or very difficult (12.5% versus 0.0%). Table 15 shows the degree of difficulty women have in obtaining ARV medication.

Table 15: Difficulty for women in obtaining antiretroviral drugs

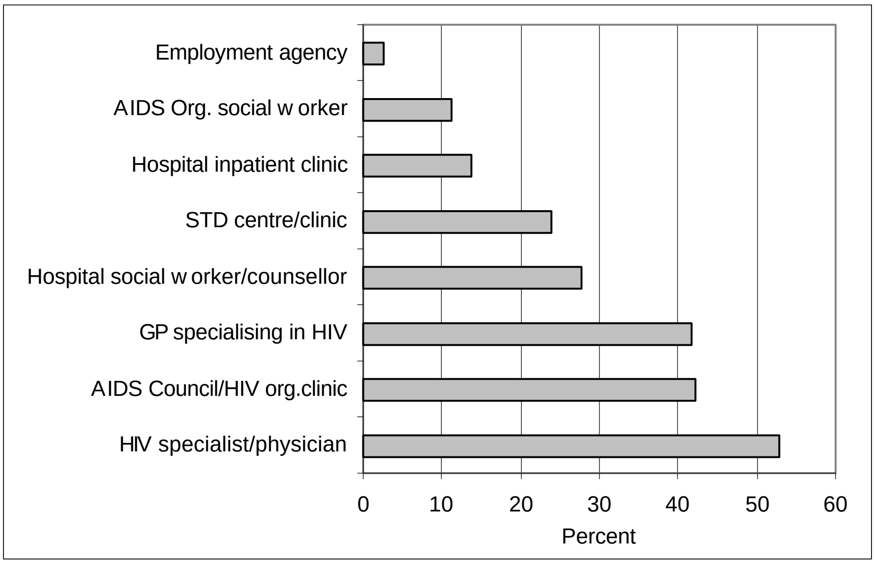
	Strongly disagree	Disagree	Agree	Strongly agree	Don’t know
It is easy for me to get combination antiretroviral drugs	3.4	4.9	60.5	28.8	2.4

N=86

Services Used in the Last 6 Months

Respondents were asked which of a list of services they had used in the past six months (see Figure 11). Not surprisingly, given the high levels of health monitoring, most women had visited either a GP who specialises in HIV (41.6%) or an HIV specialist (52.6%). More than one third of the women had visited a hospital outpatient clinic (39.6%), 13.8% had been to an inpatient clinic and 24.0% had been to an STD centre/clinic. More than one third of women had visited a clinic at an AIDS council (42.2%), 38.8% of women had used the services of a social worker, either at an AIDS council (27.6%) or hospital (11.2) and 2.5% had utilised the services of an employment agency. Almost one quarter (24.3%) of women had utilised only one of the clinical services (GP, HIV specialist, Hospital in- or out-patient clinic, STD centre, or AIDS council clinic) in the last six months, while 31.0% had utilised two services, 13.0% had utilised three services, 15% had utilised four and 16.6% had used five or more services.

Figure 11: Services used in the last six months by women



N= 88 (Multiple responses possible)

Just under half of women (45.4%) reported that they had experienced less favourable treatment at a medical service as a result of having HIV. Women were significantly more likely than men to report having experienced HIV related discrimination at a medical service (45.4% versus 30.5%).

Other Services

Participants were asked whether they currently use a range of services and, if so, whether they do so through an HIV/AIDS organisation (including Positive Women's Organisations) or through another organisation. The service at AIDS organisations most commonly used by women was treatment advice, with more than half the women selecting this item (see Table 16). AIDS organisations were also used for social contact with other PLWHA, other forms of peer support, counselling and advice on financial and legal matters. They were also an important source for alternative therapies.

Other organisations were more likely than AIDS organisations to be used for pharmacy services, mental health services, employment services and financial advice.

Table 16: Services used by women at HIV/AIDS organisations and at other organisations

	Use service at HIV/AIDS ORGANISATION	Use service at OTHER ORGANISATION
Treatments advice	54.4	15.0
Social contact with other PLWHA	49.3	8.9
Counselling	38.6	26.5
Peer support group	46.6	6.6
Financial assistance	28.6	13.2
Alternative therapies	29.9	26.3
Informal peer support	32.8	8.8
Legal advice	11.4	15.3
Pharmacy services	27.4	34.1
Housing assistance	17.5	18.8
Financial advice	7.4	19.0
Library	18.3	26.9
Internet access	13.8	18.7
Respite care	13.9	5.6
Mental health services	7.0	13.7
Return to work skills	4.7	9.4
Employment services	5.0	13.3
Drug/alcohol treatment	3.9	13.0

N=88 (Multiple responses possible)

When asked what services they feel they need but are currently not getting, women nominated career planning (7.9%), stress management (2.3%) and services in rural areas (2.3%).

INFORMATION

Sources

Respondents were asked a variety of questions about where they seek their information about issues related to being positive, such as managing side effects, discrimination, work, finances and what being HIV positive means in all aspects of their lives. Survey participants were given a list of information sources and asked which of these are important sources of information about treatments, and which are important sources of information about living with HIV. They were also asked which single source is the most important for each of these areas.

Doctors specialising in HIV were selected by 91.6% of women as an important source of information about treatments. Almost two thirds of women (62.1%) said Positive Women's Organisations were important sources of information about living with HIV (see Table 17). The single most important source of information about treatments for women are doctors specialising in HIV (64.9%). However, women said their most important source of information about living with HIV is Positive Women's Organisations (38.4%).

Table 17: Sources of information for women about treatments and living with HIV

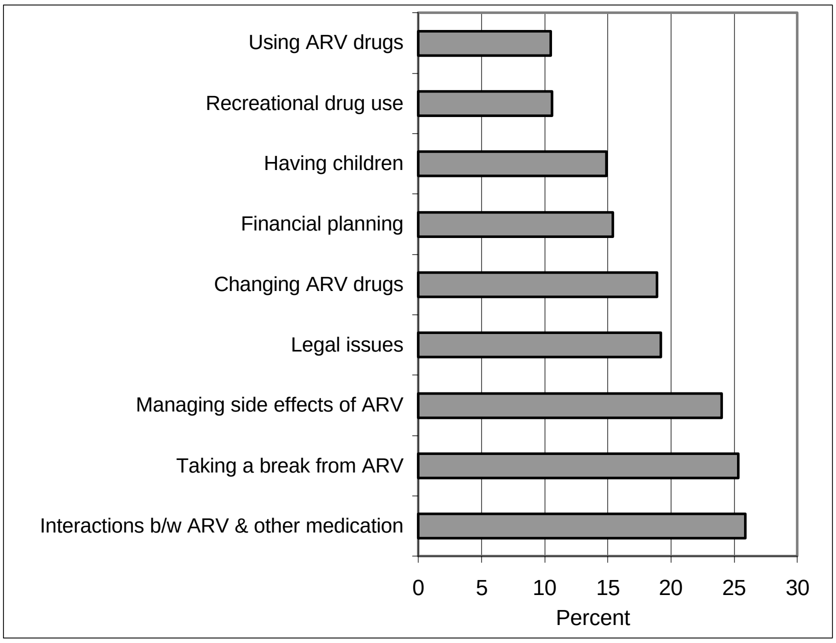
	Information about TREATMENTS	Information about LIVING WITH HIV
Doctor specialising in HIV	91.6	43.0
HIV magazine/ newspaper	64.7	57.8
Positive women's organisation	48.4	62.1
HIV positive friends	44.7	58.3
Treatments officer	28.9	8.9
Other HIV/AIDS organisation staff	28.2	39.0
Alternative therapist	27.1	25.6
Nurse	26.5	24.1
Articles in gay press	24.5	17.8
Internet	22.9	17.2
Pharmacist	15.5	4.6
Other doctor	13.7	13.5
Family	11.9	22.8
Partner/ lover	9.0	21.7
Other friends	6.7	16.8
Injecting drug users' organisation	3.4	3.8
Haemophilia Foundation	1.0	1.0

N=85 (Multiple responses possible)

Women were significantly more likely than men to report that: their alternative therapist is an important source of information about treatments for HIV/AIDS; and that their family is an important source of information about treatments for HIV/AIDS.

When asked if a lack of information made it difficult to make decisions about a range of issues, one quarter of women said interactions between ARV and other medications (25.9%), treatment interruptions/breaks (25.3%) and management of side effects (24.0%). Lack of information about legal issues (19.2%), changing ARV drugs (18.9%), financial planning (15.4%), having children (14.9%), recreational drug use (10.6%), and use of ARV (10.5%) were also reported (see Figure 12).

Figure 12: Problems experienced by women due to lack of information



N=85 (Multiple responses possible)

Publications

Respondents were asked which of a range of publications containing AIDS information they read. The results for women are presented in Table 18. The most widely read publications are Positive Living (a regular insert in the gay press, also mailed out to positive people and organisations around the country) newsletters from community organisations and HIV Herald (a magazine focusing on treatments for HIV/AIDS).

Table 18: Publications read by women

Publication	**Percentage**
National or non-specific[1]	
Positive Living	47.9
Newsletters from community organisations	45.6
HIV Herald	43.9
Gay newspapers (% of total sample)	27.3
National AIDS Bulletin	21.6
Overseas HIV/AIDS magazines (eg POZ)	15.4
Gay magazines	11.1
National Haemophilia (% of total sample)	0.0
State based publications	
Talkabout (% of total sample)	48.9
Talkabout (% of NSW respondents)	76.8
With Complements (% of total sample)	43.3
With Complements (% of NSW respondents)	48.4
NUAA News (% of total sample)	4.0
NUAA News (% of NSW respondents)	7.0
Positive Life (% of total sample)	17.9
Positive Life (% of WA respondents)	78.3
QPP Alive (% of total sample)	12.1
QPP Alive (% of QLD respondents)	83.8

[1] N=88 (Multiple response possible)

[I'm] positive. But positive in a positive outlook... Looking forward to the future with my partner and my child. Yeah, I just want to get on with things now. I feel I've wasted a lot of time. In the early days I just thought 'well there's not a lot of point in anything', so I didn't do very much. And now I feel that those years were really wasted. But I think I needed those years to get my head around the virus, where I was going, what could be done. Like gathering all the information, working it all out. And I've come out the other end, thinking 'well, I'm still here, let's celebrate'. There's nothing now to stop me doing things I wanted to do eight years ago…but in the early days I was very negative. But now I'm much more optimistic. So, yeah, optimistic, realistic and happy. And sort of chomping at the bit now to get on. I don't want to waste any more time.

Sharon, 39, diagnosed 1990

THE SOCIAL WORLD OF PLWHA

Involvement with AIDS Organisations

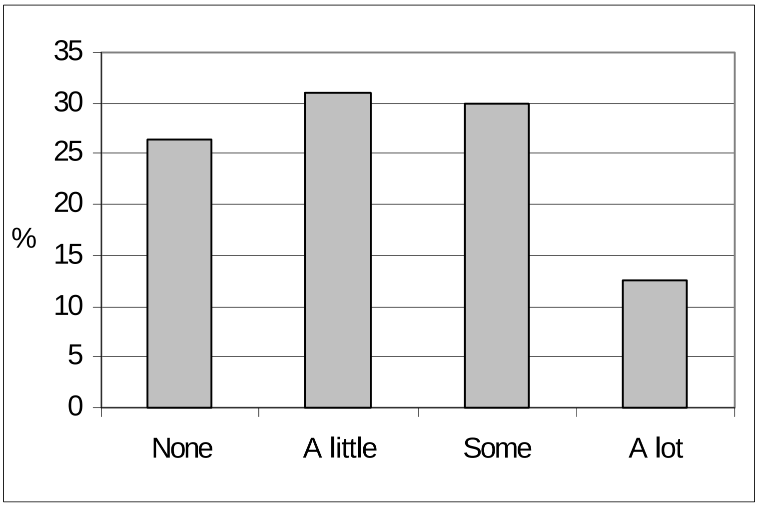
Participants were asked about their involvement with HIV/AIDS organisations. Over three quarters of women (87.0%) have some contact with HIV/AIDS organisations. Of those women who have no contact with AIDS organisations, eight women gave the reason *I do not want to be involved*, one woman said *I do not have enough time*, another woman reported she has *no transport or was too far away* and one woman said she *feared a breach of confidentiality*. Importantly, four women who are not involved in AIDS organisations said they *feel excluded from them*.

Just over one third of women (36.9%) had at some point held a decision making position in an AIDS organisation.

Contact With Other PLWHA

When asked how much of their free time they spend with other HIV positive people, women were most likely to indicate that they spend *a little time* (31.0%) or *some time* (30.0%) with other positive people while around one quarter spend *no time* (26.4%) and 12.6% spend *a lot of time* (18.7%) with other PLWHA (see Figure 13). There were no significant differences between men and women in the amount of free time they spend with other PLWHA.

Figure 13: Free time spent by women with other positive people



N= 88

When asked if they know other people who are HIV positive, 11.5% of women indicated that they know no other positive people. Almost half (49.1%) have friends who are positive and three quarters (74.3%) of women have HIV positive acquaintances. Almost one quarter (22.1%) have an HIV positive former partner (see Table 19).

Table 19: Other HIV positive persons known by women

Positive persons	Percentage
No-one	11.5
Partner/ spouse	12.5
Former partner/ spouse	22.1
Friend	49.1
Son/ daughter	5.4
Other relative	5.8
Acquaintance/ member of support group	74.3

N= 86 (Multiple responses possible for respondents who know other PLWHA)

Around one quarter of women (24.3%) have been involved in the nursing and care of someone with AIDS in the last two years. Two thirds (66.2%) of women have had someone close to them die of AIDS, primarily friends (46.2%), or acquaintances (39.1%), but also former partners/spouses (16.4%) or partners/spouses (9.0%).

Disclosure

Participants were asked who they have told that they are HIV positive. A small number (5%) of women have told no-one. Most have told close friends, and the majority have told siblings, parents, close friends, positive friends and partners. Table 20 shows the rates of disclosure for the whole sample and disclosure rates for some specific groups of PLWHA, for example, disclosure to partners among those currently in a regular relationship.

Table 20: People that women have disclosed their HIV status to

	Percentage who have disclosed
All women[1]	
Brothers or Sisters	79.0
Parents	75.2
Close friends	71.1
Partner/ spouse	59.5
Positive friends	57.0
Son/ daughter	32.2
Work colleagues	30.1
Other friends	27.9
Neighbours	13.8
People from own ethnic community	5.2
No-one	5.0
Partners (% of those in regular relationship)	90.2
Partners (% of those not in regular relationship)	19.3
Work colleagues (% of those currently employed)	38.3
Work colleagues (% of those not employed)	21.3
Son/ daughter (% of those with dependent children)	47.1
Son/ daughter (% of those with children not dependent)	17.7

[1] N=88 (Multiple responses possible)

More than two thirds (68.2%) of women said that their HIV status had been disclosed when they did not want it to be. Women who said they have experienced less favourable treatment than other people at medical services as a result of having HIV/AIDS were significantly more likely than other women to report that their HIV status had been disclosed when they did not want it to be (89.7% versus 10.3%).

The Place of HIV in Women's Lives

We were interested in how central HIV was to PLWHA's sense of identity, particularly in comparison to other aspects of themselves. To assess this we asked *When you think of all the things that make you who you are, how important are each of the following aspects of yourself?* The categories and results are given in Table 21. A rating of *essential* indicates that the characteristic is an essential component of the individual's identity. A rating of *important* indicates that the characteristic plays a large part in how PLWHA see themselves, but may have greater or lesser relevance depending on the context. A rating of *not important* indicates that the characteristic does not generally enter into their self-image. A rating of *irrelevant* indicates that the characteristic plays no part in their self-image. While our primary focus in this area was on the importance of HIV identity, we have included other characteristics, both as points of comparison and as a way of more fully describing PLWHA.

The majority (63.0%) of women in this study consider their HIV status an important, but not essential aspect of their make-up, while 10.8% consider it to be an essential characteristic. This is in contrast to sexuality and gender, where over 30% of the sample consider these to be *essential* characteristics. (See Table 21).

Table 21: Importance of personal characteristics to women's sense of identity

	Essential	Important	Not important	Irrelevant
HIV status	10.8	63.0	20.4	5.8
Sexuality	31.9	43.3	17.3	7.5
Gender	32.1	42.0	8.9	17.0
Drug use (recreational/illegal)	4.9	11.6	19.7	63.8
Ethnicity/ Cultural background	6.5	25.1	20.8	47.6
Parenthood	44.9	24.8	7.5	22.8
Career	14.3	51.9	21.0	12.8

N=79-82 N varies due to missing data

Social Support

Women have reasonably high levels of support from those in their social networks (see Table 22). When asked how much support they receive from a range of sources, the categories that rated highest were parents, partner/spouse, close friends and pets (it is difficult to compare groups as the numbers vary for each category).

Table 22: Social support received from different sources: percentage of women

	A lot	Some	A little	None	Doesn't apply
Parents	51.9	14.4	10.7	7.2	15.8
Close friends	45.7	25.7	11.6	5.2	11.8
Partner/ spouse	43.8	10.2	10.3	5.7	30.0
Pets	42.4	9.4	7.8	4.5	35.9
Brothers and sisters	41.6	15.4	19.3	10.2	13.5
Children	40.2	11.2	8.0	6.7	33.9
Counsellor	31.4	21.6	6.5	9.9	30.4
HIV positive friends	28.8	25.9	18.2	7.0	20.1
PLWHA groups	23.2	28.2	15.8	14.4	18.4
Other friends	13.0	26.9	22.0	12.4	25.7
Religious or spiritual adviser	8.6	7.9	10.6	12.6	60.3

N=71-76 N varies due to missing data

Respondents were also asked how many of the following sources they get a lot of support from: partner/spouse; friends; parents; siblings; and children. Possible results range from zero to seven sources of *a lot* of support. Most women (82.4%) rated at least one of these individuals as the source of *a lot* of support. One fifth of women (19.2%) said they have one person from whom they receive a lot of support, 18.3% said two people, 16.8% said three people, 15.2% said four people, 6.5% said five people and a further 6.5% said six people.

Mental Health

An increasingly important concern in the HIV/AIDS field has been the mental health of PLWHA. There is growing evidence that depression, anxiety, dementia and other general psychological issues are critical factors in the well-being of positive people. We included several items in the survey that addressed PLWHA's mental well-being.

Psychiatric Medications

In the last six months over one quarter (29.7%) of women had taken medication prescribed for anxiety. Slightly fewer women (22.3%) had taken medication for depression. In addition 8.5% of women indicated that they had taken anti-psychotic medication.

Symptoms of Depression

We included a set of four items modified from those in the Beck Depression Inventory (BDI), a widely used depression assessment instrument. These were: (1) I cry or feel like crying all the time; (2) I don't enjoy things the way I used to; (3) I have lost interest in other people; and (4) I don't feel it's worth going on. These four items provide an indication of some of the major symptoms associated with depression. These four items are often used in general practice as reasonable indicators for the prescription of anti-depressants. As can be seen in Table 23, a considerable proportion of women agree or strongly agree with each of the items.

More than half of the women agree with the statement *I don't enjoy things the way I used to* (55.2%) and over one third of the women agree with the statement *I have lost interest in other people* (34.2%). Almost one third (29.5%) of women agree or strongly agree with the statement *I feel like crying all the time* and 12.7% agree with the statement *I don't feel it's worth going on*.

We can look at the number of these items that women agree with as a way of measuring the extent of depressive symptoms. Overall, 38.8% of women agree or strongly agree with none of these items, 24.3% with one item, 17.1% with two items, 14.2% with three items, and 5.6% agree with all four items. Agreement with all four items is suggestive of clinical depression. Agreement with a larger number of these items is significantly related to using anti-depressant medication.

More than half of the women agreed with the statement C*hanges in my body due to HIV/AIDS have made me feel unattractive* (53.5%) and slightly more than half disagreed with the statement *I am happy with the way my body looks* (51.6%). Over half of the women also agreed with the statements *As long as I am well I prefer not to think about HIV/AIDS* and *Life has become more meaningful since I became HIV positive*.

Table 23: Attitudes relating to women's mental health: percentage of all women

	Strongly disagree	**Disagree**	**Agree**	**Strongly agree**
I cry or feel like crying all the time	15.5	55.0	21.3	8.2
I don't enjoy things the way I used to	10.0	34.7	41.0	14.3
I have lost interest in other people	23.6	42.3	25.7	8.4
I don't feel it's worth going on	50.2	37.1	6.6	6.1
As long as I am well I prefer not to think about HIV/AIDS	4.8	39.3	37.6	18.3
Changes in my body due to HIV/AIDS have made me feel unattractive	13.4	33.1	34.1	19.4
I am happy with the way my body looks	10.5	41.1	37.0	11.4
Life has become more meaningful since I became HIV positive	10.3	27.7	33.3	28.7

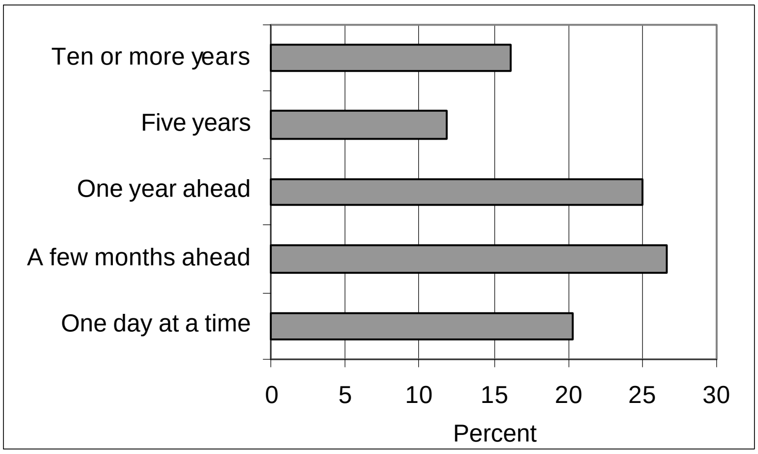
N=80-85 N varies due to missing data

Planning for the Future

One particular interest of this study is how far into the future do people plan when making decisions about their lives. In the original Futures Survey (1997), we suspected that the introduction of combination antiretroviral therapy would increase the future perspective of HIV positive people. That study found that around half of the women had changed their planning time-frame and of these, slightly less than one third were using a longer time frame, mostly as a result of improved health due to antiretroviral drugs. We repeated the questions in this survey, and overall there appears to be a continuation of the trend observed in 1997.

One fifth (20.3%) of women plan one day at a time and 26.7% plan a few months ahead. However, half of the women plan for at least a year, with 25.0% planning one year ahead, 11.8% planning five years ahead and 16.2% planning ten or more years ahead.

Figure 14: Women's time frame for future planning

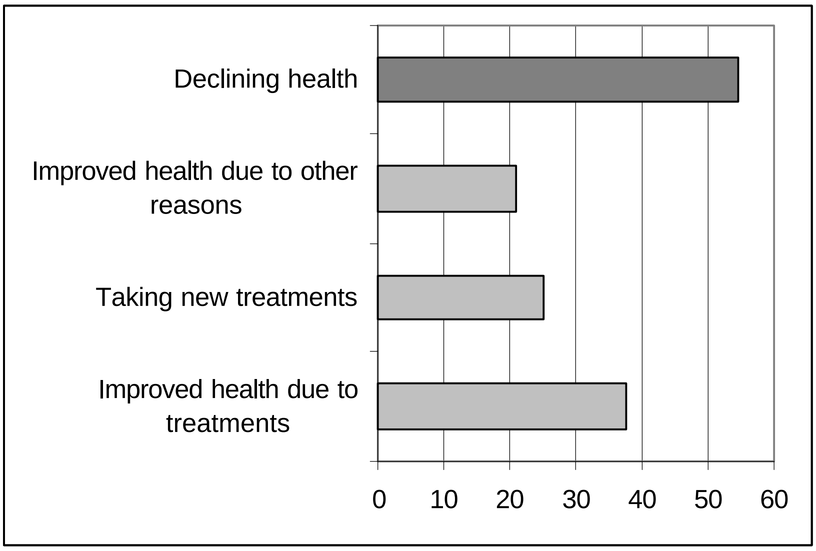


N=84

For 41.3% of women, the time frame for future planning has changed in the last two years. Of those who have changed their time-frame, 31.4% now use a shorter time-frame and 68.6% use a longer time frame. Few women have made dramatic shifts in their time-frame, with most women moving one category in the list given, particularly among those moving to a shorter time-frame.

The major reasons for change for those women with a longer time frame were: improved: health due to treatments (37.5% of those with longer plans); taking new treatments (25.0%); and improved health for other reasons (20.8%). The major reason for change for those with a shorter time frame was declining health (54.5% of those with a shorter time frame). See Figure 15.

Figure 15: Reasons given by women for change in time-frame



N=24 (longer time frame-indicated by light grey); N=11 (shorter time frame-indicated by dark grey).

And the other positive women that I've met through [positive women]… I find it really important. Not so much as a support group, because I don't really think I need a support group, I've gone past support. But the girls when I meet them … we chat … it doesn't have to be HIV related.
Sharon, 39, diagnosed 1990

Well I'm not who I really want to be. I have this ideal that I want to be happy, carefree, easygoing person. And that's who I feel I am but the circumstance and the day to day things don't allow me to be who I want to be.

I thought I'd just live with it anyway. You know, I've always been 'I'm not dying from HIV, I'm living with HIV'. Always. It was something I was told right at the very, very beginning and it's always stuck with me, always.

Lyn, 33, diagnosed 1987

WOMEN AND CHILDREN

Summary:

Half of the women surveyed have dependent children. A number of these women gave birth to their children after being diagnosed with HIV. More than half of the women with children have told their children aged 18 or younger that they have HIV.

A small proportion of women have either decided to have children in the future or are currently trying to become pregnant. However, the vast majority of women are not considering pregnancy and childbirth in the future.

Children

As mentioned earlier in this report, half (50.6%) of the women surveyed have dependent children and a number of women also have children who are over the age of 18 and no longer dependent. The ages of the 60 dependent children ranged from less than 1 year to 18 years. The average age of dependent children was 7.7 years. Of the women with children around half (50.3%) of children are aged five years and under and 29.7% of the children are aged two years and under.

Five women reported that their child is also HIV positive and one woman reported that her child had died of an AIDS related illness. Twenty-two women have had a total of 34 children born to them since they were diagnosed HIV positive.

Disclosure to children

Of the women who have told their children they are HIV positive, 43.8% said they told their child of their diagnosis when the child was 12 years or younger. A further 18.8% of women said they had disclosed to the child when the child was 18 years or younger.

Planning for children in the future

Four women said they have decided to have children in the future and three women said they are currently trying to get pregnant. Eleven women said they have thought about having a child, but have not yet decided and six women said they have thought about it but decided that it is too risky. One woman was pregnant at the time of completing the survey.

Almost three quarters of women surveyed said they are not considering having a child at this point in time. Of these women, half (50%) already have dependent children. One woman who already has dependent children has decided to have another child/children in the future. Six women who have dependent children said they have thought about it but they have not yet decided.

It is important to note here that 14.9% of women feel they do not have enough information about pregnancy and having a child.

Health and children

Women with dependent children were no more likely than women without dependent children to rate their health as excellent or good. There were no significant differences in most recent viral load or CD4/T-cell test results. Women with dependent children were also no more likely to be using antiretroviral drugs.

Relationships and children

Of the four women who said they have decided to have children in the future, three women were currently in a regular relationship or married and one was not. Of the three women who said they are currently trying to get pregnant, one woman was not currently in a regular relationship or married and the other two women were. One woman who reported that she was currently pregnant said she was currently in a regular relationship or married.

Sexual identity and children

All four women who said they have decided to have children in the future identified as heterosexual. Of the three women who said they are currently trying to get pregnant, one woman identified as bisexual and the other two women identified as heterosexual. Of the eleven women said they have thought about having a child, but have not yet decided, two women identified as bisexual and nine as heterosexual. Of the six women who said they had thought about it but had decided that it is too risky, one woman identified as lesbian and the remainder as heterosexual. The one woman who reported that she was currently pregnant identified as heterosexual. Although those who are considering, or have considered having children are primarily women (heterosexual and lesbian), some are gay, bisexual and heterosexual men. (See Table 24).

Table 24: Decision to have children by gender and sexuality of respondent

Sexual relationships	Heterosexual women	Bisexual women	Lesbian women	Heterosexual men	Bisexual men	Gay men
No – I am not considering having a child	51	2	9	51	39	693
I have decided to have a child/children in the future	3	0	0	4	5	3
I am currently trying to conceive/get pregnant	2	1	0	0	0	0
I have thought about it but I haven't decided	9	2	0	6	5	9
I have thought about it but I have decided that it is too risky	5	0	1	1	7	23
I/we are currently pregnant	1	0	0	0	0	0
Total number	71	5	10	62	56	728

You could say I'm excited about the future but my baby made so much of a difference because I always wanted to have children. And it's not that I was never allowed but it was always -- oh, I was pregnant [earlier but] I decided not to have the baby. And I just went along with - now I [realise I] should have just dug my heels in. So [my baby's] really planned and really wanted now… you just wake up every morning, you just have to pinch yourself.

Sharon, 39, diagnosed 1990

…I don’t want to tell [my child] that, like him being -- having AIDS, too soon because then [my child] will go round telling friends, you know, ‘my Daddy had AIDS’. You know [my child] doesn’t understand the connotations. Just ‘my Daddy’s dead’ and that’s it. But -- yeah [it will] be interesting as [my child] gets older.

Allison, 38, diagnosed 1996

But then I went up to hospital with my child and I said ‘I want you to give my child the same thing I’m having. It’s worked for me’. And they said ‘you can’t do that, it’s not the same person, - a child also, so you can’t do that’. But they only put [my child] on two of the drugs. And I said I didn’t see the point of that. I thought that was really stupid. I thought they should have straight away put [my child] on the three… So…I’m angry with them because … I feel that I should have been advised better when I was pregnant, to take AZT. And I should have been advised about other, a lot of other issues that just weren’t forthcoming. And if I had been -- okay I’m supposedly intelligent, I went to high school, I can read and write, but … what’s the point of them sitting there and having contact with you if they’re not going [through] that stuff.

Carmen, 35, diagnosed 1985

SEX AND RELATIONSHIPS

Summary:
Half of the women reported that they are in a regular relationship or married. It is interesting to note, however, that 41.4% of women are not currently sexually active. One-third of women in a regular relationship or married have a partner who is also HIV positive. Use of condoms with regular partners was related to the partner's HIV serostatus, such that women whose regular partner is HIV negative are significantly more likely to always use condoms, whereas few women with HIV positive regular partners always use condoms.

A small proportion of women had sex with a casual partner in the 6 months prior to completing the survey. The majority of these women always used condoms during sex with casual partners.

Many women appear unsure of the impact of HIV on forming new relationships, and the impact of HIV on sexual pleasure. Few women agree that new treatments make safe sex less important, or that they feel more confident about unprotected sex because of the new treatments.

In HIV Futures II, as in HIV Futures I, we asked about the practice and experience of sex among positive people. We have asked about sexual practice, in part, because it is important to continue to affirm that PLWHA have sex, particularly when sectors of society believe this is undesirable. In part this is also because sex is an important part of life for many people, and in order to understand the things that make people who they are, we need to understand the sex they have. We also asked about sex as it relates to HIV transmission in recognition of the critical role that HIV positive people have in education and prevention. We asked about the experience of sex, because our previous and current research tells us that being HIV positive can have a profound influence on how people feel about and negotiate their sexual lives and be important for health and well-being. We asked about the experience of relationships, because we are aware that this too can be profoundly influenced by being HIV positive.

Relationships

Respondents were asked which types of sexual relationships they currently have. The results are presented in Table 25 below. Slightly more than half of the women (56.7%) said they are currently in a regular relationship or married. This is slightly higher than the proportion of women that report having sex with a regular partner (Table 25 - 46.0%), because some women in a regular relationship or married do not have sex. It is interesting to note, however, that 41.4% of women are not currently sexually active

Table 25: Type of sexual relationship(s) by gender and sexuality of respondent

Sexual relationships	Women	Heterosexual men	Homosexual & bisexual men	Total
Regular relationship only	46.0	37.3	22.5	25.6
No sex at present	41.4	49.8	21.5	25.5
Casual sex only	6.9	11.1	32.7	28.8
Regular relationship plus casual sex	5.7	1.9	20.4	17.7
Regular with two or more people	0.0	0.0	3.0	2.5

N=87 (Women) N=61 (Heterosexual men) N=791 (Homosexual and bisexual men)

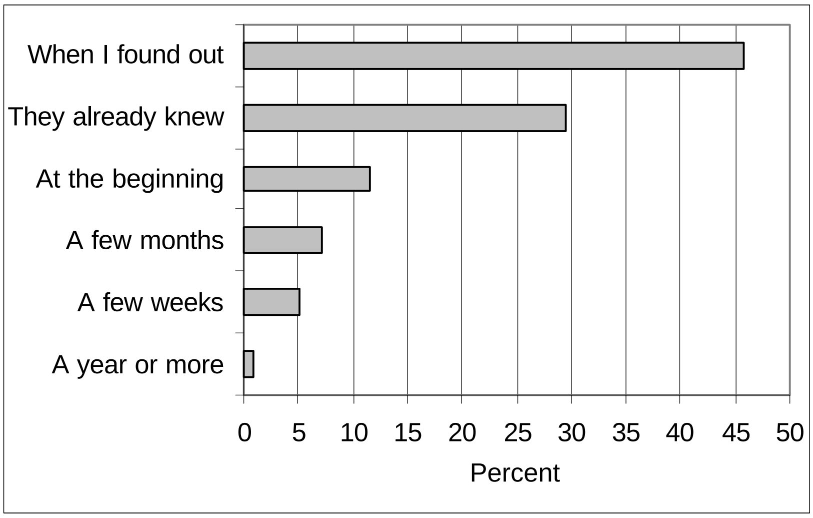
Regular Partners

Of the women in a regular relationship or married, 31.7% report that their partner is also HIV positive (generally described as a sero-concordant relationship). The remainder are in sero-nonconcordant relationships. This second group is made up of 61.3% of women who report that their partner is HIV negative (a sero-discordant relationship) and 7.0% report that they don't know their partner's HIV status.

Disclosure to partners

All of the women who are in regular relationships or married have told their partner that they are HIV positive. Respondents were asked at what point in the relationship they told their partner. The responses given by women are illustrated in Figure 16 below. Around half (45.7%) of the women told their partner when they themselves found out they were positive. Slightly fewer than a third (29.4%) told their partner at the beginning of the relationship and for 11.5% of respondents, the partner knew prior to the start of the relationship. Small numbers of women told their partners a few weeks into the relationship (5.2%), 7.2% a few months into the relationship, and 1.0% a year or more into the relationship.

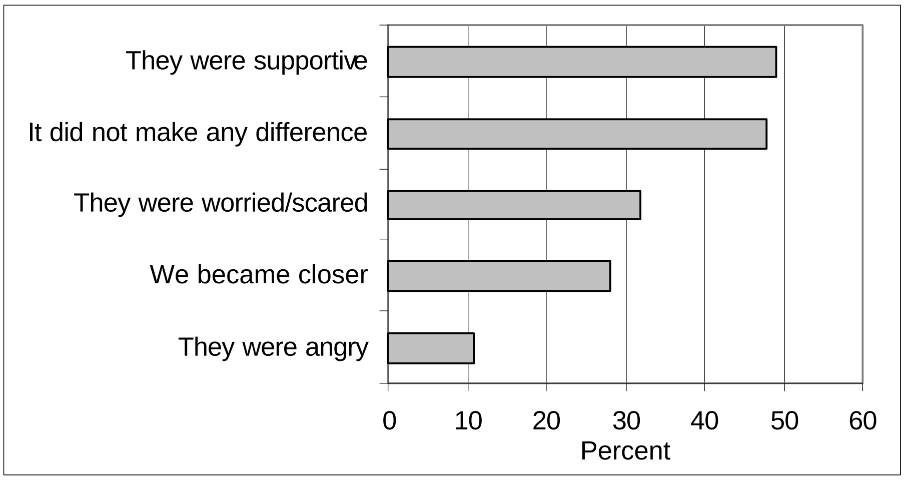
Figure 16: Women's disclosure of HIV status to regular partners



N=49

When asked how their partner responded when told of the woman's HIV status: 49.1% reported that their partner was supportive (see Figure 17); 47.9% reported that it did not make any difference; and 28.1% reported that the disclosure brought them closer together. Almost one third (32.0%) reported that their partner was worried or scared and 11.0% said their partner was angry.

Figure 17: Reaction of partner to disclosure



N=48

Sex with regular partners

Almost half (47.6%) of women had vaginal and/or anal sex with a regular male partner in the six months prior to completing the survey. In addition, two women (2.4%) reported vaginal and/or anal intercourse with regular female partners. About one fifth of women reported that they never used condoms with male partners and more than half reported that they always used condoms (see Table 26).

Table 26: Condom use with regular partner by respondent and partner gender

ALL relationships	**Percentage of these that used condom**		
	Never	Sometimes	Always
Female respondents			
With regular male partner [1]	22.2	22.1	55.7
With regular female partner [2]	50.0	0.0	50.0

1: N=41, 2: N=2

If we look at these data in terms of relationship sero-concordance unprotected vaginal or anal intercourse is more likely to occur in sero-concordant relationships than in sero-nonconcordant relationships (see Table 27).

Table 27: Condom use with regular partner by partner gender, and partner sero-status

SERO-CONCORDANT Relationships	**Percentage of these that used condom**		
	Never	Sometimes	Always
Female respondents			
With regular male partner [1]	46.2	15.3	38.5
With regular female partner [2]	0.0	0.0	0.0
SERO-NONCONCORDANT Relationships			
Female respondents			
With regular male partner [3]	12.5	29.2	58.3
With regular female partner [4]	50.0	0.0	50.0

1: N=13, 2: N=0, 3: N=24, 4: N=2

Sex with casual partners

One fifth (19.7%) of the women reported that in the six months prior to completing the survey they had sex with one or more casual partners. When asked the HIV status of their casual partners, 3.6% reported that all of their casual partners were HIV positive, 13.2% reported that some of their casual partners were HIV positive, and 26.8% reported that they did not know the

HIV status of their casual partners. Most (56.5%) women who had casual sex reported that none of their casual partners were HIV positive.

Respondents were asked about their condom use during anal or vaginal intercourse with casual partners over the previous six months. Of the ten women who reported condom use with casual male partners, nine reported that they always used condoms and one woman said she never used condoms. Of the three women who reported condom use with their casual female partners, one woman said she always used condoms, one woman said she sometimes used condoms and another woman said she always used condoms.

Only 12 women (15.2%) reported both the serostatus of their casual partners and condom use with these partners in the six months prior to completing the survey. Of the women who said their partners were both a mixture of HIV positive and HIV negative partners or that they were unsure of their partners status four women said they always use a condom and one woman reported that she never used condoms. Of the women who reported that their partners were HIV negative two women said they sometimes used condoms and five women said they always used condoms. No women reported having all HIV positive casual partners.

In addition to reporting on their overall patterns of condom use, women who had casual sex reported on their most recent sexual encounter with a casual partner. Fifteen women (17.4%) provided such information. Of these, half of the women (51.2%) had sex with a HIV negative partner, one fifth of women (20.3%) reported that they did not know the HIV status of their most recent casual partner and 28.5% had sex with an HIV positive partner. Respondents who indicated that they knew their partners' HIV status were asked how they knew. All of the women said that their partner told them their status.

Two thirds of women (67.5%) who reported their most recent causal sexual encounter had vaginal and/or anal intercourse. Of these women, nine women (81.8%) used a condom and two (18.2%) did not use a condom. As was found for the overall patterns of condom use, condom use during women's most recent sexual encounter was related to the HIV status of the partner. Of the two women who said their most recent casual partner was HIV positive, one woman used a condom and one did not. Of the three women whose most recent casual partner's serostatus was unknown, two women used a condom and one woman did not and of the five women who reported that their most recent casual partner was HIV negative, all women used a condom.

Respondents who had vaginal and/or anal intercourse with their most recent casual partner were also asked about ejaculation. Of the two women who did not use condoms for intercourse with their most recent casual partner, one woman reported that their partner ejaculated inside them.

HIV, Sex, Relationships and Treatments

Survey participants were asked to respond to a number of statements about relationships, sex, and HIV. The results of these items are shown in full in Table 28.

When asked whether they would prefer to be in a relationship with someone who is also HIV positive, almost two thirds of women (62.8%) said they would not, 15.7% said they would and 21.5% said that they do not know. Women in sero-concordant relationships were more likely to agree with this statement than both women in sero-nonconcordant relationships and women not currently in relationships. Men were more likely to agree with this statement than were women.

One critical issue for PLWHA is the impact that HIV has on the potential to develop new relationships. More than two thirds (70.4%) of women agree with the statement *Few people would want a relationship with someone who has HIV.* There were no differences between women in regular relationships and women not in regular relationships in responses to this statement.

A similar response was found to the statement *I am afraid of telling potential partners of my HIV status in case they reject me.* Over half the women (56.5%) agree with this statement. When asked to respond to the statement *People with HIV now have a better chance to form partnerships and relationships*, over half of the women agree, around one quarter disagree, and the remainder are unsure.

When we examine the impact of HIV on sexual pleasure, we find that almost two thirds of women (65.1%) agree with the statement *HIV has had a negative effect on my sexual pleasure*. Over one quarter (28.1%) disagree with this statement.

When asked about the relationship between partners' HIV status and sexual pleasure there was a greater degree of uncertainty. Almost one quarter were unsure when asked to respond to the statement *If I know that my partner is HIV positive I find sex more pleasurable*. Almost half of the women disagree with this statement and a large number of women were unsure. Men were significantly more likely than women to agree with this statement.

The fear of infecting a partner with HIV is an important issue for those surveyed. Almost three quarters of women agree with the statement *I am afraid of infecting my partner or potential partner with HIV.* Very few women agree with the statement *I feel more confident about* *unprotected sex because of new treatments*. Most women disagree with the statement, and over half strongly disagree. Respondents were also asked to respond to the statement *New medical treatments for HIV/AIDS make safe sex less important than it was*. The vast majority of women disagree with this statement. Similarly, the vast majority of women disagree with the statement *Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom*. Most women also disagree with the statement *Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV*.

The possibility of a preventive vaccine has raised issues of its potential impact on condom use. Participants were asked if they agree with the statement *If there was a vaccine which prevents HIV, I would not practise safe sex*. The majority of women disagree with this statement and the remainder of women were equally divided between agreement and uncertainty. Women are significantly less likely than men to agree with this statement.

At first I was devastated because I thought I might never have sex again. And while my mother was saying ‘oh God, she’s going to die’, I was saying ‘oh my God, I’m not going to have sex again’. It was the hugest thing for me. Not so much just sex but the relationship and that was really, really hard. Who’s going to love me now? But part of me just believed that I would meet someone. But it was really hard, yeah.

But I had been out with a couple of guys who were [positive], but it just wasn’t right and there’s no way that I wanted … that to be the only basis of a relationship. And I’d heard stories about people meeting negative guys, positive women meeting negative guys and how it had gone well. [And I thought] Wow it can really happen. So I was starting to believe that I would meet someone.

Narelle, 30, diagnosed 1997

Because having AIDS is like a ball and chain. You can’t do anything with it, you know. You can’t have unprotected sex, you’ve got to use a condom. There’s no ifs, buts or maybes… then you’ve got the guys who just won’t.

But going out and doing it. It feels like I’m one of those young teenagers again that has to start all over again, and not knowing where to start. And yeah, I’d love a relationship. Maybe not someone living here, but just to have someone in my life -- yeah, just the companionship of another -- like opposite sex, just sitting there and cuddle up and just -- I don’t know, just relaxing with someone. I miss all that kind of stuff.

Catherine, 31, diagnosed 1990

I think when my health was on a slow downhill turn over the last decade, I think I went through different stages where I just kind of went into total denial that I don’t’ ever want to or need a sexual relationship again. And then I think I went through a long period of just loneliness. And probably wouldn’t quite articulate or acknowledge, probably wasn’t even that conscious in terms of wanting a partner but I think what I really wanted was comfort, someone to put their arm around me. I don’t think I wanted sex as such. And now I think probably because I’m healthier, I’m probably a more sexual being. But because now I’m ten years older than when I was dying, I don’t actually see myself as having a sexual future

Miranda, 48, diagnosed 1991

Table 28: Women's attitudes to HIV, sex and relationships

	Strongly Disagree	Disagree	Agree	Strongly agree	Don't know
I prefer to have a relationship with someone who also has HIV	25.8	37.0	6.2	9.5	21.5
Few people would want a relationship with someone who has HIV	5.9	20.6	51.1	19.3	3.1
I am afraid of telling potential partners of my HIV status in case they reject me	7.7	24.4	36.8	19.7	11.4
People with HIV now have a better chance to form partnerships and relationships	10.9	15.3	47.8	9.3	16.7
If I know that my partner is HIV positive I find sex more pleasurable	18.1	28.0	12.0	1.6	40.3
HIV has had a negative effect on my sexual pleasure	9.7	18.4	44.2	20.9	6.8
I am afraid of infecting my partner, or potential partner, with HIV	9.0	16.4	40.5	31.8	2.3
I feel more confident about unprotected sex because of the new treatments	60.2	25.6	2.2	7.1	4.9
New medical treatments for HIV/AIDS make safe sex less important than it was	59.6	30.9	3.4	0.0	6.1
Undetectable viral load means HIV is unlikely to be transmitted to a sexual partner even if I have sex without a condom	51.1	30.5	6.1	1.2	11.1
Withdrawing before ejaculating (cumming) is a way to reduce the risk of passing on HIV	42.7	36.6	9.3	1.0	10.4
If there was a vaccine which prevents HIV, I would not practise safe sex	33.3	33.9	8.4	8.9	15.5

N = 82-85

RECREATIONAL DRUG USE

Summary:

Rates of recreational drug use among HIV positive women appear to be similar to those found in the general population. However, HIV positive women are less likely than HIV positive men to use recreational drugs. Few women reported that they have experienced bad interactions between ARV drugs and recreational drugs, or that using illegal drugs has caused them to miss a dose of ARV drugs. Few women feel that they use alcohol or other drugs more than they would like to.

Two-thirds of women have never injected illegal drugs, but 11.9% indicated that they had injected illegal drugs in the 12 months prior to completing the survey. One of these 10 women reported that she shared needles in this time period and that the person with whom she shared needles with was also HIV positive and Hepatitis C positive.

Practices

Respondents were asked about their use of a range of non-prescription drugs, both those legally available and those that are prohibited in Australia. The questions were asked in such a way as to allow comparison with the results of the *National Drug Strategy Household Survey* of drug and alcohol use conducted by the Australian Institute of Health and Welfare (AIHW). Respondents were asked which of a list of substances they had used in the last year. For those drugs which are commonly injected, differentiation was made between injection and other means of administration. Table 29 gives the results of these items and lists the comparable rates for the Australian population from AIHW's 1998 survey (AIHW, 1999).

Table 29: Use of non-prescription drugs; women, men and general population rates[5]

	% of women using in last 12 months[1]	% of men using in last 12 months[2]	General Population rates[5]
Alcohol	67.5	83.8	80.7
Cigarettes	37.5	56.2	26.4
Marijuana	36.7	57.6	17.9
Methadone (prescribed)	11.2	5.3	N/A
Speed (injected)	8.8	11.0	3.6*
Heroin (injected)	7.0	8.2	0.7*
Ecstasy	6.5	24.5	2.4
LSD/ trips	4.7	13.3	3.0
Amyl	4.1	42.7	0.8
Heroin (not injected)	1.7	1.0	0.7*
Cocaine (not injected)	1.3	8.7	1.4*
Methadone (other)	1.2	1.4	0.2
Speed (not injected)	1.0	19.4	3.6*
Steroids (injected)	0.0	6.0	0.2
Cocaine (injected)	0.0	3.6	1.4*

1: N=82; 2: N=834 (Multiple responses possible)

*Rates in the AIHW report do not differentiate between injected and administered through other means. General population rates given are for any use of the substance.

Table 29 reveals that although alcohol, the most commonly used drug, is used by a comparable proportion of the PLWHA populations and the general population, women are significantly less likely than men to drink alcohol. It is also important to note that among PLWHA, that women are significantly less likely than men to: smoke cigarettes; use non injected speed; use non injected cocaine; take ecstasy; use marijuana; take LSD/trips; take amyl; or use steroids. The differences in consumption of some of these drugs may be due to the popularity of these drugs in the gay and dance party scenes. Women were significantly more likely than men to use prescribed methadone.

It must be noted that we only asked respondents if they had used each of the drugs in the previous twelve months, not how often they use them.

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[5] Source: 1998 National Drug Strategy Household Survey AIHW NB: A gender breakdown was not available for all drugs.

Two thirds (62.9%) of women reported that they have never injected illegal drugs, while 11.9% had done so in the last twelve months and 17.6% have done so more than twelve months ago. Seven women did not indicate whether or not they have ever injected illegal drugs.

Three women reported that they have had a bad experience from using both antiretroviral drugs and illegal drugs such as nausea/vomiting, weight loss and liver damage. Nine women (10.6%) reported that they have missed a dose of antiretroviral medication at some point as a result of using illegal drugs.

Of the 10 women who reported injecting drugs in the last twelve months, one woman reported sharing needles in that time period. This woman reported that she did not have access to other needles and that the person with whom she shared needles was also HIV positive and Hepatitis C positive.

Attitudes Relating to Drug Use

A small number (13.7%) of women feel that they drink more alcohol than they would like to and 17.0% feel they use more illegal drugs than they would like to. As specific quantities of drugs used was not asked in this survey, this is not necessarily a measure of substance abuse, but rather gives an indication that there are important areas of health maintenance among HIV positive women that need to be addressed. One woman agreed that sharing needles is not a problem if your viral load is undetectable and 12.2% of women agree that they worry about infecting others by sharing needles. (See Table 30).

Table 30: Women's attitudes relating to drug use and infection

	Strongly disagree	Disagree	Agree	Strongly agree	Not applicable
I drink more alcohol than I would like to	44.4	18.4	8.1	5.6	23.5
I use illegal drugs more than I would like to	27.6	11.2	13.7	3.3	44.2
I worry about infecting others by sharing needles	4.8	2.8	0.0	12.2	80.2
Sharing needles is not a problem if your viral load is undetectable	57.7	8.1	0.0	1.0	33.2

N=78-80

Well it's hard to tell when I was taking another drug as well, you know. It was pretty hard to tell. But I didn't know – as I was coming off methadone, which was really, really bad, it became more apparent to me that I was having side effects. Particularly when I changed over to another sort of medication.

Rachael, 46, diagnosed 1994

We all started smoking like mad when we [were] diagnosed because we were all [thought] we weren't going to die of lung cancer, we were going to die of AIDS. And it's like, 'oh God, I've been doing this for ten years now', and it's like, now I might make a serious effort with that this year. Because I've suddenly got the possibility of longevity.

Miranda, 48, diagnosed 1991

ACCOMMODATION

Summary:
Three quarters of women find their accommodation unsuitable for their needs, most commonly because it is too small, too expensive, or too far from services. A substantial minority of women have changed their accommodation as a result of HIV/AIDS. The most commonly cited reasons for changing accommodation were to move closer to health services and to find cheaper accommodation.

Approximately one third of women own or are purchasing their own house or flat (36.1%) and almost one quarter (23.3%) live in rental accommodation. More than one fifth (22.6%) of women are in Government rental accommodation, while the remainder live in housing provided by friends or family (10.6%) or in community housing (7.3%). Half of the women live with a partner or spouse (45.2%) and almost half live with dependent children (46.6%). One fifth (20.3%) of women live on their own and 14.5% live with other family members. Some live with friends or a housemate (7.1%).

Almost three quarters of women (72.5%) find their accommodation suitable for their current needs. Of those who do not, the most commonly reported problems was that the accommodation is too small (47.5%) or too expensive (33.7%). More than one third of women reported that their accommodation is too far from services (41.6%), that it does not provide adequate privacy (27.0%) or that it is in poor condition (24.2%). When asked if they have ever changed their accommodation as a result of HIV/AIDS, 42.1% said they have. For these women, the most commonly reported reasons were: moving closer to health services (39.2%), moving because of illness (30.8%), and moving to cheaper housing (30.4%). One fifth of women who had changed their accommodation as a result of having HIV/AIDS moved to avoid harassment. See Table 31.

Table 31: Reasons given by women for changing accommodation

	% of women who had moved
Moved closer to health services	39.2
Illness	30.8
Moved to cheaper housing	30.4
To avoid harassment	20.6
Planning for illness	18.1
Better health	17.8
Moved to a quieter location	17.6
Moved closer to friends	16.5
Moved closer to other services	15.6
Stopped working	14.2
Moved in with family	14.2
Looking for/ returned to work	8.0
Ending of long term relationship	7.2
Beginning of new relationship	4.5
Improved finances	3.9
Moved out of family home	1.4

N=37 (Multiple responses possible)

Oh, they tried to run me out of town. We sold the house…It was just madness … the other one we had to move away from because of the neighbourhood people. When they find out, you know, when they find out they just hassle you, they don't understand. And … I arranged to take one of the kids to a child care centre and I had to walk past these people's place all the time. And I was so scared all the time. Because they just kept wanting to hassle me.

Maggie, 33, diagnosed 1986

Well sometimes being in a commission place it didn't take long for people to work out things. Some of them would be very cruel.

Rachael, 46, diagnosed 1994

EMPLOYMENT

Summary:

Fewer than half of the women who completed the survey are in paid employment and most of those who are employed work part-time.

Although nearly all women indicated that being diagnosed with HIV affected their career plans (eg stopping work or changing careers), fewer than half indicated that combination ARV therapy has affected their career plans.

Half of the women indicated that at some time they have stopped work for reasons related to their HIV diagnosis. Fewer than half of these women subsequently returned to work. Those who returned to work did so because of better physical health, better psychological health, or financial necessity.

Around half of the women in paid employment reported that their work capacity is reduced by HIV/AIDS because they tire more quickly, have to work reduced hours, or have difficulty concentrating. Most of the women in paid employment reported that their employer gives them flexibility to take time off when they are sick or to attend medical appointments, however, they had less flexibility to take time off for counselling.

Employment Status

Fewer than half (40.2%) of the women are currently in paid work (see Table 32). More than one fifth (21.0%) of women are engaged in home duties and the majority of the remainder described themselves as either not working or retired. Of those who are working, the mean number of hours worked per week is 27.2 (40.6 hours/week among those working full time; 18.5 hours per week among those working part time.

Table 32: Employment status of women

	Percentage
Volunteer work	3.3
Student	7.0
Unemployed	10.3
Not working/ retired	18.2
Home duties	21.0
Working full time	17.2
Working part time	23.0

N=85

Four in ten women (41.7%) do volunteer work: 28.2% for an HIV/AIDS organisation; 10.5% for another type of organisation; and 2.3% for both types of organisation.

When asked what impact their diagnosis of HIV had on their career plans, one third of women (33.9%) said that they stopped working, or that HIV ended their career, and 15.2% said that they changed careers. Slightly less than one third (29.2%) reported that they found it more difficult to plan for the future and a smaller number of women (14.8%) said that they no longer saw their career as important. One in five women (22.3%) indicated that their HIV diagnosis did not change their career plans.

Respondents were asked what impact combination antiretroviral therapy has made on their career plans. Over half of the women using ARV therapy said that there had been no change (see Table 33).

Table 33: Impact of antiretroviral therapy on women's work plans

	Percentage
There has been no change	55.1
Anticipate longer time in work force	8.4
Considered new career plan	7.3
Stopped work	6.3
Went back to work	6.0
Considered going back to work	5.5
Considered stopping work	3.7
Made new career plan	3.2
Now have a work plan	2.0
Started work	1.5
Started studying	1.0

N=63

Respondents were asked if they have stopped work at any time since their HIV diagnosis. Of those women who have worked, 52.1% had stopped work for reasons related to HIV at some point. This work interruption averaged for 3 years and 1 month (range 1 month to 12 years). The circumstances relating to the most recent interruption to employment are given in Table 34 below. The most common response was poor health (57.4%). Over half of the women cited diminished energy levels, and slightly less than half cited stress, depression, or anxiety as reasons for stopping work.

Table 34: Circumstance surrounding last interruption to women's employment

	Percentage
Poor health	57.4
Low energy levels	50.7
Stress/ depression/ anxiety	44.2
To move to diff location	20.8
Expecting illness in future	19.5
To have more time to self	14.3
To care for someone with HIV	8.5
Retrenched/ sacked	7.9

N= 41 (Multiple responses possible)

At the time that women had most recently stopped working while positive, 14.7% had been diagnosed with an AIDS defining illness, 39.0% had been ill (but not with an AIDS defining illness) and 46.2% had not been ill. When they were not working, the main source of income for almost two thirds of women was a government benefit (62.8%) while smaller numbers relied on superannuation (12.8%), salary from other sources (15.1%), partner support (6.5%) or family support (3.3%).

Of the women who stopped working at some point, 43.2% had returned to work. This was most commonly because of better psychological health (see Table 35), although financial reasons and better physical health, more flexible hours, or a shift to part time work were also important.

Table 35: Women's reasons for returning to work

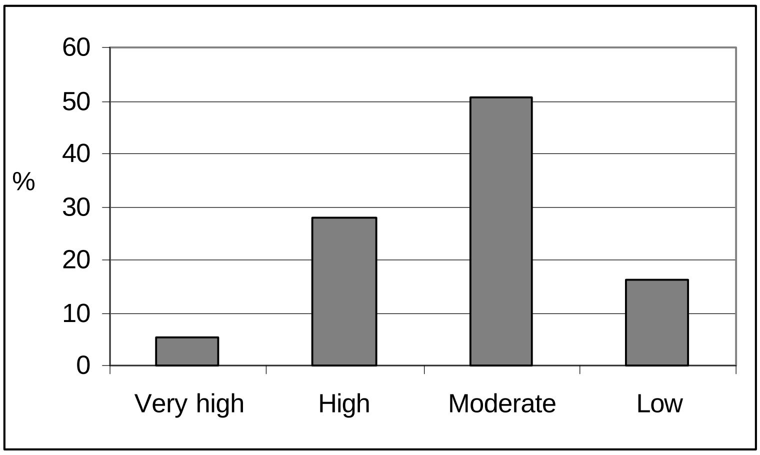
	Percentage
Better psychological health	63.5
Financial reasons	54.2
Better physical health	43.0
Possibility of flexible working hours	39.8
Possibility of part-time work	38.0
To do something worthwhile	37.3
To have more social contact	37.2
To have something to do	28.7
Became self employed	5.5

N=18 (Multiple responses possible)

Women Currently in Paid Employment

Respondents who are working were asked about the level of stress in their current job. Half of the women rated the stress level as moderate (50.6%) while an additional 28.1% said it was high and 5.2% said it was very high. Around one in six women (16.1%) said there was low stress (see Figure 18). One third (29.9%) of employed women work in an HIV/AIDS related field. Women working in a HIV/AIDS related area were no more likely to report higher stress levels than women working in other fields.

Figure 18: Women's stress at work



N=36

One workplace issue for many HIV positive people is the confidentiality of their HIV status. When asked what difficulties they have with confidentiality at work, less than one third of employed women said that they do not attempt to keep their status confidential (see Table 36). Around half said they have experienced no problem in this area (both those who disclose and those who do not). Of those who do experience difficulties, the greatest problem appears to be gossip, followed by visible signs of illness and explaining absences from work. Not surprisingly, women who work in an HIV related job are less likely to wish to keep their status confidential and have fewer problems when they do choose to do so.

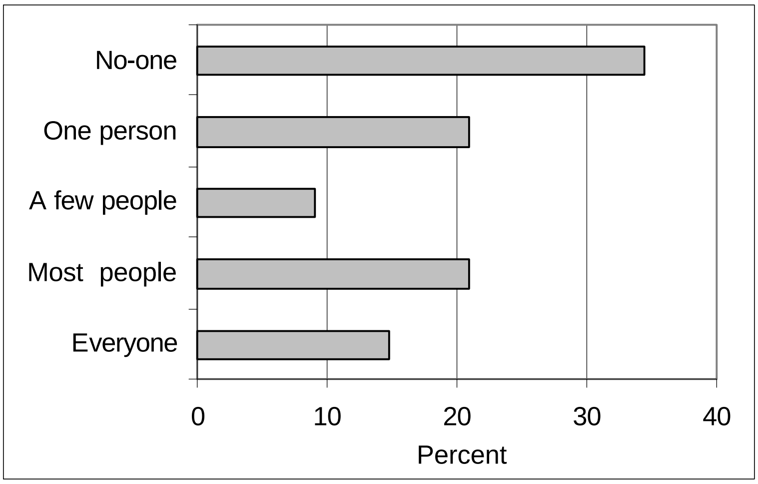
Table 36: Difficulties with women's HIV status confidentiality in the workplace: percentages of all women and specific samples.

	All women[1]	Those not working in HIV related job[2]	Those working in HIV related job[3]
I do not try to keep my status confidential	29.7	15.8	62.4
No problems	49.8	55.7	35.7
Gossip	15.9	17.7	11.9
Visible signs of illness	12.5	17.8	0.0
Explaining absences from work	11.1	15.8	0.0
Difficulty keeping and taking medication	7.1	10.1	0.0

1: N=37; 2: N=26; 3: N=11 (Multiple responses possible)

When asked how many people in their workplace know that they are HIV positive, 14.7% of women said that everyone knows, 20.9% said most people know, 9.1% said a few people know, 20.9% said one person knows and 34.4% said no-one knows (see Figure 19).

Figure 19: Women's disclosure in workplace



N=37

When asked about the impact that HIV has on their capacity to perform their work duties, around half of the women said that their work is unaffected (see Table 37). One third said that they tire more quickly, and a substantial proportion said that they have reduced their work hours, or that they have difficulty concentrating. Women who report no impact on their capacity tend to be those who give more favourable ratings of their general health.

Table 37: Impact of HIV on women's work capacity

	Percentage
Not affected by HIV	53.1
I tire more quickly	34.4
I work reduced hours	18.8
I have difficulty concentrating	17.5
I am less productive	9.1
I cannot always go to work	3.6

N=37 (Multiple responses possible)

Managing HIV infection requires a degree of flexibility in the workplace to attend medical appointments, to manage changes in treatment, side effects of treatments, illness and the psychological impact of HIV. Respondents were asked how much flexibility their workplace gives them to take time off for reasons relating to HIV. The majority of women have the capacity to take time off for medical appointments (see Table 38) and illness. There was less capacity to take time off for counselling and few can take time off to engage in volunteer work.

Table 38: Capacity within workplace for women's HIV related interruptions

	Never	Seldom	Sometimes	Often	Always
For medical appointments[1]	7.1	0.0	19.8	15.9	57.2
For counselling[2]	30.8	5.4	16.6	7.6	39.6
When you are sick[3]	6.0	3.7	8.0	13.8	68.5
To do volunteer work[4]	54.5	0.0	9.7	19.2	16.6

1:N=33; 2:N=24; 3:N=32; 4:N=20

One in seven women (14.2%) said they have experienced less favourable treatment at work as a result of their HIV status.

Anticipated Changes in Work Life for Those Working and Those Not Working

One third (35.6%) of women said that they plan to change their work arrangements. Of these, around half said they want to change the type of work that they do and almost as many said they plan to start work or return to work (see Table 39). The majority of women indicated that it will be difficult to make the desired change to their work arrangements.

Table 39: Women's plans for changes to work life and anticipated difficulty

		Difficulty		
	Percentage	Not at all	Somewhat	Very
I want to change the type of work I do	53.4	12.5	50.0	37.5
I want to start/ return to work	41.6	8.3	66.7	25.0
I want to reduce my work hours	23.8	0.0	66.7	33.3
I want to increase my work hours	12.3	50.0	50.0	0.0
I want to stop work	3.6	0.0	100.0	0.0
I want to broaden my skills	3.6	0.0	0.0	100.0
I want flexibility	3.6	0.0	0.0	100.0
I want to be self employed	3.6	0.0	100.0	0.0
Total		12.4	54.6	33.0

N=31 (Multiple responses possible)

The main incentives for changes in work arrangements are financial (see Table 40). Among women who intend to start work or return to work, the primary motivations are to commence work after training or studying, to do something worthwhile, for social contact, or for financial reasons.

Table 40: Reasons for changes to work plans among women

	All women
Financial reasons	57.4
To do something worthwhile	51.0
To have more social contact	47.8
To reduce stress	38.7
Better psychological health	36.5
To have something to do	30.8
Better physical health	25.9
Possibility of flexible work hours	25.8
Possibility of working part-time	19.2
Possibility of working full-time	16.0
Worse physical health	6.5
Nearly finished training/studying	6.5
Worse psychological health	4.0
Need more challenge/stimulation	3.2

N=31 (Multiple responses possible)

Respondents were asked how they spend their time while not working. Each respondent indicated the three activities that occupy most of their time. Slightly fewer than half identified housework and over a third said they spend their time resting or participating in leisure activities (for example reading). Socialising with close friends and looking after children were also listed by around one quarter of women. (See Table 41).

Table 41: Activities pursued while not working: percentage of all women

	Percentage
Housework	43.1
Resting	34.1
Leisure activities	34.1
Socialising with close friends	26.1
Looking after children	22.7
Volunteer work in HIV/AIDS organisation	7.9
Volunteer work in other organisation	5.7
Study	4.5
Looking after another HIV positive person	4.5
Socialising with HIV positive friends	3.4
Spend time with family	1.1
Socialising with other friends	1.1

N=88 (Up to three responses per participant possible)

I haven't actually worked full time for a number of years now, because I got quite sick …and I was advised by my doctor I should just kind of take it easy, slow down a bit and get on the pension. And I've been on and off the pension for the last maybe four years, but now I'm trying to do a bit more. Thinking of going back to study actually. When [my child] goes to school hopefully I can go to work. I've done childcare, administration work and hospitality. Sort of leapt between the three. But now [I might] try and combine them all together. [I'm] looking at studying part time and then hopefully when [my child's] school age I will have finished [and can] get back in the work force.

Sharon, 39, diagnosed 1990

There's certain areas I won't work in any more… I will not work in certain industries… one reason is that I don't' have that much energy. Even though I'm still much, much better than I was before I started the antiretrovirals … I only work from home basically…But I've only got about six hours work in me, you know, a day.

Carmen, 35, diagnosed 1985

I think when I wasn't working, even though I had a young child, it was like I'm not working because I'm not well enough to work and they were sort of expecting me sort of sitting at home waiting to die in a sense. I mean that's over-dramatising it somewhat but since I'm working – other people who work and live not so called normal lives, [it] has given them some sense of my life being similar to theirs. I suppose they can relate more to me as a working mother who goes about life as everyone else does. And maybe they've got other things to focus on now in my life rather than the HIV.

But I think that since I've been working and becoming involved it's probably making [me] a better mother and better friend and I'm interacting with different people I suppose. Before I went back to work I was very much sort of spending time mostly with my family, my close family and a few friends. Whereas I suppose that's sort of winded out now and attracting more people and sort of discussing issues sort of thing.

Janelle, 32, diagnosed 1991

Oh being positive was a complete and utter change in my life... it completely shattered my self esteem at the time. It certainly changed the course of my career… And in that time…it completely changed me, changed me utterly. Changed the way you look at life and your priorities and what's important and what's not important anymore. So, yeah, it made a profound shift for me. Emotion and thinking.

Miranda, 48, diagnosed 1991

FINANCES

Summary:
More than half of the women who completed the survey report that their major source of income is a government benefit and one-third receive their income from a salary. It is important to note that 45.7% of women reported an income below the poverty line, and that the majority of women dependent on a government benefit live in poverty. Women were significantly more likely than men to report an income below the poverty line. However, women who shared their financial resources with a partner or spouse were significantly less likely to live in poverty than women who did not.

Many women report difficulty meeting their costs of living. The items most commonly reported as being difficult to afford related to social activities. However, a substantial proportion of women report that it is very difficult for them to pay for clothing, food, and utilities such as gas and electricity.

Income

The 1997 HIV Futures study showed that many PLWHA were suffering financial hardship, particularly those receiving a government benefit. In the 1999 study respondents were once again asked the source of their income and these data are presented in Table 42. Over half of the women identified their main source of income as a benefit or pension, while one third receive a salary.

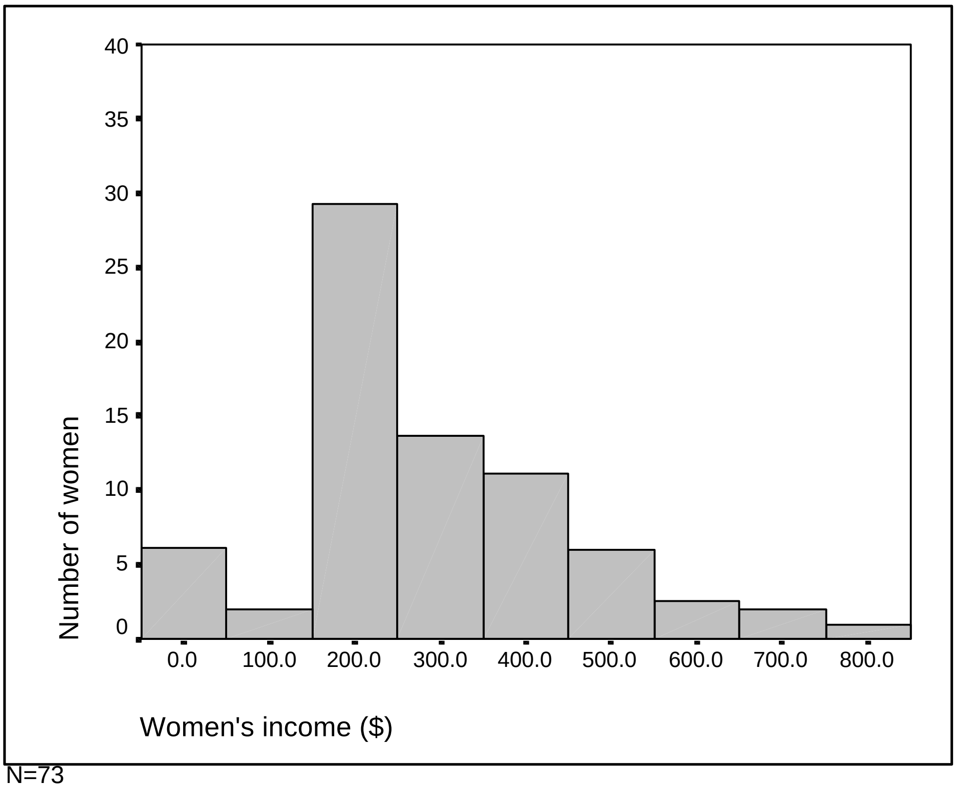
Table 42: Primary source of women's income.

Source of income	Percentage
Benefits/ Pension/ Social security	53.2
Salary	33.5
Partner supports me	8.7
Superannuation	4.0
Family/friend support me	0.6

N=81

Respondents were asked their weekly after-tax income and women's responses ranged from $0 to $800.00 with a mean of $276.75. Figure 20 shows the distribution of after-tax weekly incomes in blocks of $100. This figure shows that most women have an income below the mean. The peak of the distribution at $150-$250 largely represents those receiving a government benefit. Women reported significantly lower incomes than men (mean weekly after-tax income of $276.75 compared to $373.75 for men).

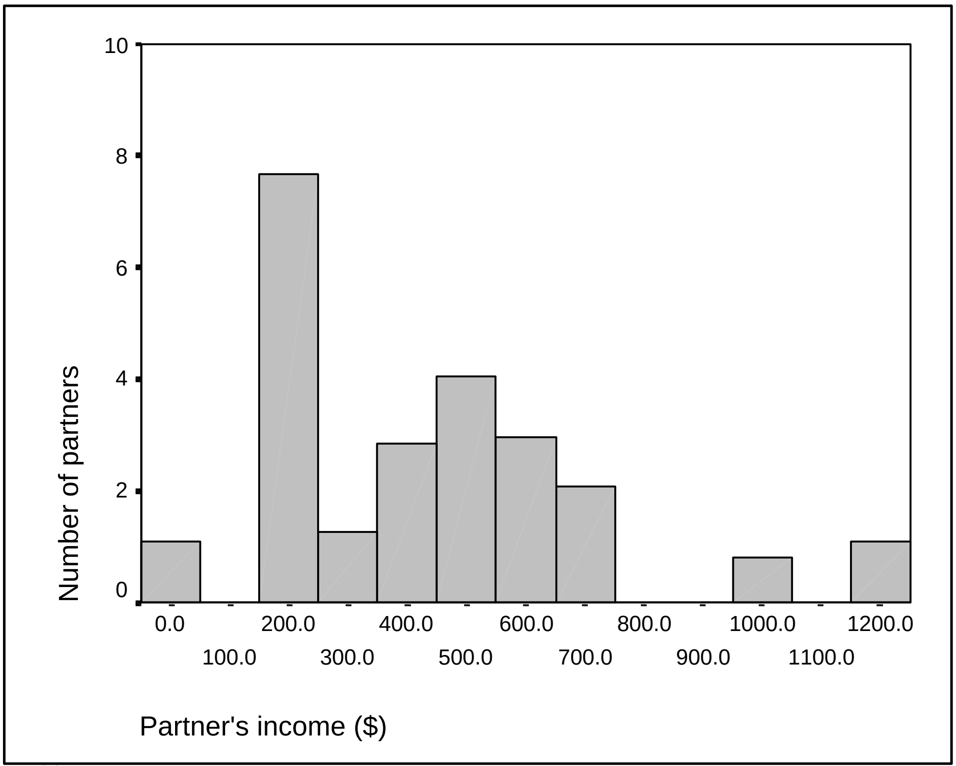
Figure 20: Histogram of women's income



N=73

Just over a quarter of women (27.1%) said they have a partner with whom they share financial resources. For these women, their partner's average weekly after-tax income was $418.01. Partners' incomes are shown in Figure 21. Six women said that the person with whom they share financial resources or who provides financial support is also HIV positive. Partners who are also HIV positive have a lower average income than those who are HIV negative (mean weekly income after-tax of $146.90 versus $460.82)

Figure 21: Histogram of women's partner's income



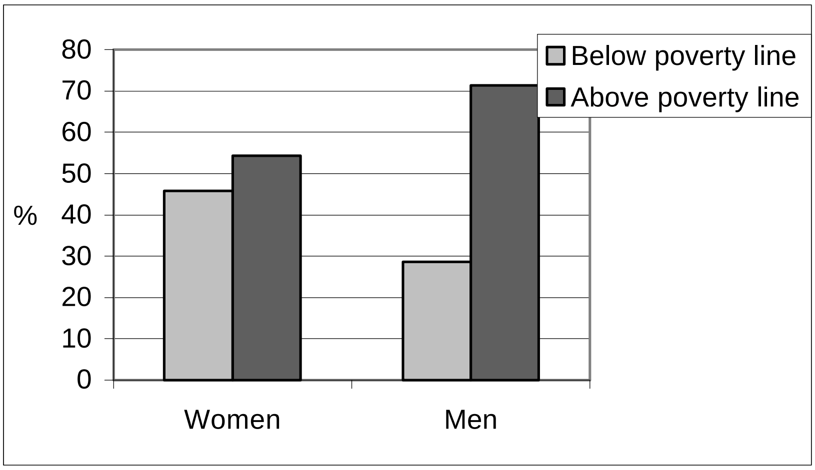
N=23

Poverty

As with the 1997 survey, we have used the quarterly Henderson Poverty Lines published by the Institute of Applied Economics and Social Research (IAESR) to assess the extent of poverty among PLWHA. The Henderson Poverty lines are set for specific *income units*. These units include the individual, any partner with whom they share financial resources and any dependant children. We used the IAESR (1999) data for the September quarter of 1999 (the time at which the survey was completed). According to an equivalent measure, 30.0% of women in the 1997 Futures survey were living below the poverty line. The 1999 Futures survey reveals that the situation has not improved for women living with HIV/AIDS with 45.7% of women now living below the poverty line.

In contrast to the 1997 survey, where no gender difference in the proportions of people living below the poverty line was found, this survey has found that women are significantly more likely to fall below the poverty line (45.7% of women versus 28.7% of men – see Figure 22). This difference existed in spite of the fact that women were no less likely to be in paid employment. Women were, however, more likely to have dependant children and this, in combination with the lower average income reported above, may go some way to explaining the difference.

Figure 22: Poverty by gender



N=815

Women in paid employment are significantly less likely than women who are not employed to be classified as below the poverty line. More than two thirds of women not in paid employment are living in poverty. See Table 43.

Table 43: Women and poverty by employment status

	Below poverty line	**Above poverty line**
In paid employment[1]	13.8	86.2
Not in paid employment[2]	68.3	31.7

1:N=29; 2:N=41

Women who identified a salary as their primary source of income are significantly less likely than other women to report an income below the poverty line. Most women on a government benefit are living in poverty. See Table 44.

Table 44: Women and poverty by income source

	Below poverty line	**Above poverty line**
Income from salary[1]	3.8	96.2
Income from government benefit[2]	80.0	20.0

1:N=26; 2:N=35

Not surprisingly, women who share financial resources with a partner are significantly less likely to be below the poverty line than those women who do not share financial resources. One quarter of women (27.1%) have a partner with whom they share financial resources, and one quarter of these women fall below the poverty line (see Table 45).

Table 45: Women and poverty by shared income status

	Below poverty line	Above poverty line
Shared financial resources[1]	25.0	75.0
Sole income[2]	54.9	45.1

1:N=20; 2:N=51

Women in a regular relationship or married are more likely to fall below the poverty line if their partner is also HIV positive. However, for women poverty is not related to having an AIDS defining illness, length of time HIV positive, use of ARV therapy or use of complementary therapies.

Fewer than one fifth (17.9%) of women have private health insurance. Women are no less likely than men to have private health insurance.

Fewer than one fifth (18.4%) of women own their own home, while 20.5% are in the process of paying off their home. The majority of women (61.1%) live in rental accommodation or other forms of accommodation.

On those women who pay either rent or mortgage, the average weekly rent/mortgage payment is $125.90. The average weekly costs of medication for women who use ARV drugs is $7.05. Women who use other medication spend an average of $15.40 per week on such medication. Women who use complementary therapies spend an average of $18.93 per week on these treatments.

Costs

Participants were asked how much difficulty they have meeting the costs of various items and activities. These ranged from the basics of life like food, clothing, housing and medication, to those things that improve well-being, health and quality of life. The results are given in Table 51, ordered from those items most likely to be found *very difficult* to afford to those least likely. Quality of life items are the most difficult for women to afford, with at least half finding it very difficult to pay for travel, socialising, recreational drugs and entertainment. Four in ten women have great difficulty paying for clothing and a further 39.9% have some difficulty. Among women with children, two thirds have at least some difficulty paying for child care.

One third of women experience considerable difficulty paying for utilities (gas, electricity and water) and over half the women experience at least some difficulty with the cost of food, housing, transport and medical services. (See Table 46).

Table 46: Difficulty for women paying costs of items and services

	Very Difficult	A little difficult	Not at all Difficult
Travel/ Holidays	67.1	18.1	14.8
Going out	47.5	33.7	18.8
Recreational drugs	57.3	24.3	18.4
Entertainment	50.9	28.5	20.6
Clothing	41.9	39.9	18.3
Sport	40.5	31.8	27.6
Child care	34.6	30.8	34.6
Utilities	31.0	48.3	20.7
Complementary therapies	43.5	27.6	28.9
Medical services	30.7	32.6	36.7
Rent/ Mortgage	17.8	52.8	29.4
Transport	22.9	43.8	33.3
Food	21.1	38.2	40.7
Support services	27.9	19.3	52.8
Other prescribed medication	21.6	35.7	42.7
Co-payments for medication for HIV/AIDS	18.5	37.7	43.8

N=20-83

Poverty and Services

Given the relationship between poverty, income, employment and the difficulty in paying for basic needs, it is not surprising that women experiencing poverty differ in the services they access. If we examine the difference between those below and those above the poverty line in terms of the use of services offered by AIDS Councils (see *Service* section page 45), we find that women living in poverty are more likely to access financial assistance and respite care.

Women below the poverty line are also more likely to use housing services at other organisations.

Women who are below the poverty line are significantly more likely to have difficulty paying for food, rent/mortgage/housing costs, utilities and sporting activities such as gym (see Table 47).

Women are significantly more likely than men to report difficulty paying for medical services, co-payments for HIV/AIDS medication, other prescribed medication, complementary therapies, support services, transport and entertainment.

So the weekends are very limited anyway, you can't, unless you've got money to pay for taxis, which I haven't, but you've still got to have money for that. But when I get a car we won't be as isolated as much. I mean we don't even go and see our friends, our friends come here. And so, I get sick of this, you know, that we can't even go and visit.

Catherine, 31, diagnosed 1990

Table 47: Difficulty for women paying costs of items and services by poverty

	Below poverty line[1]				Above poverty line[2]			
	Very difficult	A little difficult	Not at all difficult	Not applicable	Very difficult	A little difficult	Not at all difficult	Not applicable
Travel/ Holidays	66.2	6.8	4.9	22.1	42.9	14.6	22.2	20.3
Entertainment	59.6	17.8	12.4	10.2	35.5	36.8	24.3	3.4
Going out	53.6	33.9	9.1	3.4	38.2	27.8	32.8	1.2
Clothing	48.9	36.9	14.2	0.0	37.6	35.3	27.1	0.0
Utilities	43.5	45.6	10.9	0.0	15.6	44.4	32.0	8.0
Sport	36.7	8.5	13.7	41.1	13.1	25.9	17.8	43.2
Food	36.3	42.6	21.1	0.0	6.0	35.2	55.6	3.2
Complementary therapies	30.0	9.2	31.8	29.0	37.8	25.7	23.0	13.5
Medical services	28.8	14.8	37.0	19.4	17.0	30.5	34.7	17.8
Transport	27.9	36.0	29.3	6.8	13.9	44.1	35.3	6.7
Recreational drugs	25.3	3.0	6.0	65.7	14.5	7.1	7.2	71.2
Other prescribed medication	25.2	16.1	42.1	16.6	6.3	30.9	36.9	25.9
Rent/ Mortgage	23.9	45.5	19.0	11.6	5.7	47.5	33.7	13.1
Support services	13.8	2.5	26.5	57.2	7.4	16.2	22.4	54.0
Co-payments for medication for HIV/AIDS	12.1	21.6	28.0	38.3	5.5	17.8	33.3	43.4
Child care	8.8	6.9	7.9	76.4	6.3	9.0	11.7	73.0

1:N=29-32; 2:N=33-38

CONCLUDING COMMENTS

A Complex Uncertainty provides an overview of the social and health status of women living with HIV in Australia. The data that has been presented suggests that trajectories of antiretroviral treatment usage differ for women, they are more likely to delay the commencement of treatment, and are less likely to be using antiretroviral therapy than HIV positive men. This is reflected in the concern that women express about the continued efficacy of treatment and the impact of side effects. We must exercise caution in interpreting the differences in treatment uptake, for this does not necessarily represent a lack of access or information, but for many women is a considered decision in the light of current knowledge about these treatments.

The importance that children play in many positive women's lives is clearly evident in the report's findings. Decisions around having children, disclosure and parenting are not simple when one considers the burden of treatment and the possibility of illness. The challenges for PLWHA in developing and maintaining family relationships continue to be significant ones.

Poverty among positive women, as demonstrated by this study, is a significant barrier to health and well-being. This is in part a reflection of the structural inequalities facing women, both globally and in the Australian context. The challenge for service providers and policy makers is to address this disadvantage in ways that respect the cultures and choices of positive women.

In a large part this report also emphasises the similarities between women and men living with HIV, reminding us that there is a collective responsibility to respond to those issues that disadvantage PLWHA, both in terms of health outcomes and quality of life. There is also just cause to celebrate the collective achievements that continue to ensure a voice and influence for Australian PLWHA.

The research that we conduct at the *Living With HIV Program* does not happen in isolation, it relies on the sustained and selfless contribution of the positive population and the organisations that serve and represent them. The funding of programs such as this recognises the contribution that social research makes to the health and well-being of PLWHA in Australia.

I've sort of had to -- for the first seven years it's been positive, I didn't want to accept the fact that -- what was wrong. Since having pneumonia, I've accepted what is wrong, but I will never accept what's going to happen. There's no way, God, that I'm going to accept and be prepared for that. No. I want to be here for my kids. There's no ifs, buts or maybes. [If] they said I'm going to die tomorrow, I'd be like 'get fucked you don't know what you're talking about'. It's like -- I can't bring myself down to that level. I've watched too many people draw on the fact that they were positive and they just wait. You don't dwell on it. You can't focus your life on it, because it will take control of your life. And AIDS is not your life, your life is <u>your</u> life. Your kids, whatever's around you….AIDS has to take a back seat.

Catherine, 31, diagnosed 1990

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