
Standing on shifting sand

Women living with
HIV/AIDS in Australia

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Acronyms Used in the Report

ACON	AIDS Council of New South Wales
AFAO	Australian Federation of AIDS Organisations
AIDS	Acquired Immune Deficiency Syndrome
HIV	Human Immunodeficiency 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
WAAC	Western Australian AIDS Council

1 Executive Summary

The HIV Futures Survey draws together the largest sample of people with HIV/AIDS to have been surveyed in Australia. The survey was conducted from 1 July 1997 to 5 September 1997. The 925 respondents represent over eight percent of the current population of PLWHA in Australia. The survey has good national coverage with respondents from all States and Territories, and from both rural and urban locations.

This report illustrates the experiences and attitudes of the 84 women who completed the HIV Futures Survey. It looks at the experiences of being a HIV-positive woman in Australia and where appropriate it highlights the differences between HIV-positive women and men.

The survey examines five main issues: health, relationships, community life, finances, and employment. The section on health focuses on PLWHA's experiences of, and attitudes toward, the new anti-viral treatments, in particular the new class of protease inhibitor drugs which have become increasingly available since the latter part of 1995. The section on relationships explores the changing nature of relationships with family, friends and partners, as well as sexual practice. The section on community examines the role of HIV/AIDS-related organisations and publications. The section on finances examines the experience of poverty and changes in accommodation. The section on employment explores the movement of PLWHA in and out of the work force.

Health Status and Management

Most women who completed this survey have taken both a CD4/T-cell test (99%) and viral load test (92%). This includes those women who are not currently using anti-viral treatments.

Almost three-quarters (73%) of the women rate their health as being excellent or good. However, almost one-third (31%) of women report that they have Hepatitis C. A range of other health conditions were also reported such as psychological or psychiatric conditions, cardiovascular disease and hypertension.

Although more than half of the women think that their doctors are more knowledgeable than themselves about treatments for HIV/AIDS (58%), the vast majority of women (89%) reported that they work together with their doctor in their decision-making around treatments. This supports the reputation of Australian PLWHA of being pro-active and involved in the management of their own health.

Women were quite divided on when they think PLWHA should begin anti-viral treatments. Almost three-quarters of the women either disagree (38%) or are unsure (35%) when asked whether PLWHA should begin anti-viral treatment as soon as possible.

Anti-viral Treatments, Prophylaxis and Complementary Therapies

A significantly smaller proportion of the women than men reported that they are currently using anti-viral treatments (61% vs 76%). However, of those women who are not using anti-viral treatments, most reported that their health did not warrant it (viral load counts below 50,000 copies/mL and CD4/T-cell counts above 250 copies/mL).

Almost two-thirds of women (63%) using anti-viral drugs reported that they experience side-effects. The vast majority of these women (91%) also reported that they experience difficulties in taking their medication, which included remembering to take their medication on time or having to adapt sleep patterns to the treatment regime (66%) and organising meals around medications (48%).

The significance of the relationship women have with their doctors is revealed in the finding that, of those women using anti-viral treatments, the vast majority (86%) decided to do so on the advice of their doctor.

One-quarter of the women (26%) who are not using anti-viral drugs reported having done so in the past. The most commonly cited reason for discontinuing use was the severity of the side-effects. The majority of women (83%) not using anti-viral treatment said they would do so in the future if their health declined. Also cited as an influencing factor in the decision to begin anti-viral therapy is the belief in the efficacy and/or safety of the treatments (53%).

There was a significant difference between men and women in the belief that new treatments have brought hope and better prospects for PLWHA. Men were significantly more likely than women to report that combination anti-viral treatments mean better prospects for most PLWHA (59% vs 37%). This difference is highlighted by the finding that one-third of women (33%) reporting that they believe anti-viral drugs are harmful. At the same time, more than two-thirds of women (70%) expressed a belief that new anti-viral drugs will be developed in time for them to gain benefits.

Compared to men, women are significantly less likely to be using prophylaxis for PCP (29% vs 47%), and significantly less likely to be using prophylaxis for other opportunistic infections (22% vs 38%). Overall, women are significantly less likely than men to be using any prophylaxis for opportunistic infections (37% vs 56%).

Two-thirds of women reported using complementary therapies. More than half use vitamin or mineral supplements (52%), one-third use massage (35%), and about a quarter used herbal therapies (24%) or meditation (23%).

Relationships and Sex

Almost two-thirds of women (64%) said they are in a regular relationship or married and women were most likely to report that they have a monogamous regular relationship (60%).

Of those women in a regular relationship, about two-thirds (63%) are in sero-nonconcordant relationships (that is, where their partner is known to be HIV-negative or their status is not known).

Almost all women (95%) who are in regular relationships have disclosed their HIV status to their partner. Most frequently, women said that their partners were very supportive in reaction to this disclosure (69%).

Women were divided on their feelings about the impact of new treatments on relationships. Half (50%) agree that they are more optimistic about the future than they were a year ago, although almost half (46%) disagree. Women were generally less optimistic than men about the future (50% vs 69%).

Generally women do not agree that HIV/AIDS is a hindrance to developing long-term relationships (66%) but half (51%) worry about rejection by potential sexual partners in response to the disclosure of their HIV status. Women are significantly more likely than men to say that they worry that nobody would want a relationship with someone who has HIV (64% vs 46%).

The vast majority of women (91%) disagree that the availability of new treatments has made them more confident about having unprotected sex.

With both regular and casual partners, more than half of the women who engaged in sexual intercourse with their partners reported using condoms if their partner is HIV-negative or if they do not know their partner's serostatus.

Community Life and Community Organisations

All of the women have disclosed their HIV status to at least one person. Of those women with dependent children, almost two-thirds (62%) have told their children that they are HIV-positive. More than one in ten women (11%) said that they have experienced discrimination at some stage. Half (49%) reported that they have changed their plans for the future in the last two years. Whilst most of these changes were positive, almost one-quarter (23%) were negative due to declining health.

When seeking advice about treatments for HIV/AIDS, women most commonly cited HIV/AIDS media as their main source of information (80%). HIV-positive friends were the most popular for information about living with HIV/AIDS (59%). Women were significantly less likely than

men to cite their doctor as their main source of information for both treatments (77% vs 92%) and living with HIV/AIDS (47% vs 65%).

Most women (86%) have some involvement with HIV/AIDS organisations. More than half (60%) are in contact with a Positive Women's group, almost half (45%) are in contact with an AIDS council and fewer than one-third (28%) are in contact with a PLWHA organisation. (These findings are likely to be influenced by the fact that these organisations were a distribution source for the survey). Most commonly, contact with organisations tended to be in the form of newsletters or mailouts as well as treatments advice and social contact. Of those women who do not have any contact a small number said that they either did not know how to join or they fear being identified.

Most women (95%) know at least one other HIV-positive person, most commonly acquaintances (74%), friends (66%), past sexual partners (29%) or present sexual partners (21%). Similarly most women (71%) spend a little or some of their free time with other HIV-positive people. Almost half (46%) of the women reported having been involved in the care of another person with HIV/AIDS at some stage.

Only a small number of women (15%) said they consider themselves part of the gay community, and of this number half of the women identified as lesbian or bisexual. Despite this, two-thirds (67%) said they read gay press and more than one-third said they go to gay venues (38%). These numbers may be explained by the fact that women report that they rely on gay newspapers and other gay media for information about treatment (21%) and living (11%) with HIV/AIDS. It may also reflect the extent to which an "HIV community" in Australia has been located within the gay community.

Finances

One-third (30%) of the women who completed the survey reported an income below the poverty line - a similar proportion to that found amongst men. Women were less likely to have an income below the poverty line if they had a partner with whom they share financial resources.

Many women have difficulty meeting their costs of living. The majority of women have difficulty meeting the costs of travel/holidays, restaurants, and entertainment. However, the majority of positive women also have difficulty affording the cost of the basics of life such as utilities (gas, electricity, etc.), housing costs, clothing, and food. Nearly all (92%) of the women with dependent children find it difficult to meet the costs of child care. Women with an income below the poverty line have greater difficulty meeting the costs of utilities and transport.

Many women with an income below the poverty line also have few assets. This means that many who currently experience financial difficulty are likely to also experience financial difficulty in the future.

Housing and accommodation

Half (53%) of the women who completed the survey live in rental accommodation, while a third (33%) live in a house they own or are purchasing. Many women (39%) live with their partner or spouse, and many (43%) live with dependent children.

The vast majority (87%) of the women believe that their accommodation is suitable for their needs. While women appeared to be satisfied with their current accommodation, nearly half (45%) had at some time changed their living arrangements as a result of being HIV seropositive. Most commonly, women had moved closer to support services.

Employment

Almost two-thirds (64%) of the women who completed the survey are not in paid employment, and most (54%) of the women who are working are employed part-time. Two-thirds (70%) of the women reported that being diagnosed HIV seropositive affected their career plans. Typically, women had greater difficulty making career plans for the future.

Most of the women who are working have told at least some of their work colleagues that they are HIV seropositive. Amongst women who have not told people at work, many have difficulties keeping their HIV status confidential.

At some stage, half (48%) of the women have left work due to HIV/AIDS. Nearly half (47%) of these women subsequently returned to work. Most commonly they returned to work for psychosocial reasons (e.g., depression, boredom) or for financial reasons.

Many of the women who were employed at the time of completing the survey are considering changing the type or amount of work they do. Half (55%) of the women who were not employed at the time of completing the survey were considering starting work or returning to work. Many women believe that it will be difficult for them to make their desired change in employment status.

Two-thirds of the women using combination anti-viral therapy said that starting this therapy had affected their career plans. These women generally felt better able to plan a work career.

2 Introduction

This report presents information on a number of aspects of the lives of women with HIV in Australia. The data were collected as part of a wider study, called the HIV Futures Study, which includes all groups of people living with HIV in Australia, and concerns issues of health, relationships, community life, finances and employment.

The information in this report goes some way to filling in the gaps in what we currently know about the experience for women of living with HIV or AIDS. In many ways the experiences of Australian women with HIV have been hidden from view, and obscured by the twin pressures of a pandemic which in global perspective has affected women disproportionately, but within Australia has left women with HIV/AIDS as a minority within a minority.

Nevertheless, Australian women have been affected by the HIV/AIDS epidemic since its outset, and today there are women living with HIV/AIDS in all States and Territories of Australia, in rural and urban areas, and from all strata of society. This study reports on their experiences across a range of issues of daily importance, and indicates some of the ways in which different groups of women experience HIV differently, and ways in which women differ from men in their experience of HIV.

The HIV Futures Survey included 925 respondents, of whom 84 were women. These women represent some 13% of the total estimated number of women currently living with HIV/AIDS in Australia.

Women, as with all people living with HIV/AIDS, live in a changing environment. Some of those changes are relatively slow, such as the gradual coming to terms with AIDS across the whole of Australian society. It remains an open question as to how far Australians have accepted the realities of AIDS, with the continuing experience of discrimination against people with HIV/AIDS suggesting there is still some way to go. Other changes have been more recent and more rapid, such as new treatments available since late in 1995 which have apparently improved prospects for the clinical management of HIV and attendant diseases. The HIV Futures Study takes as one starting point an investigation of the various ramifications of changed perceptions and experiences of HIV on the ways in which people with HIV/AIDS live their lives.

As well as those things which women living with HIV/AIDS have in common with men, there are many aspects of their experience of HIV which are distinctive. Issues around child bearing and rearing are much more prominent in the lives of women with HIV/AIDS in Australia, and include matters such as caring for an HIV-positive child, avoiding infection of a child or a partner, and disclosure of HIV to children. This study also provides additional evidence of the ongoing financial pressures faced by women with HIV/AIDS, especially those who are sole parents. As well, women with HIV/AIDS in Australia face particular issues in finding support

and building community. Women with HIV have faced a constant struggle for their voices to be heard. This experience has in some sense been the opposite to that of gay men, the largest group affected by HIV in Australia, where there has been an all too ready association of homosexuality and AIDS.

This report is largely based on the HIV Futures Survey. The Survey is the major part of a wider HIV Futures Study which also includes two related long interview studies, one focussing on relationships and one on work. The interview studies are designed to give more detailed and nuanced accounts of some of the major issues reported in the quantitative data. This report illustrates the Survey data with some quotes from women in the interview studies. Later reports will analyse in more detail the results of the interview studies.

This report aims to further knowledge and understanding of the experiences of women living with HIV/AIDS in Australia, and how the longer term impacts of HIV/AIDS and of new treatments affect the choices made by women with HIV about relationships, moving into and out of work, and community participation. We hope it will provide government and community bodies with a better understanding of these issues, and will be used to inform strategic and policy decision making. Above all, though, we hope it will provide to all women living with HIV/AIDS in Australia a better sense of how their lives and experiences relate to those of other HIV-positive women.

For me a very big part of my life is Positive Women and, when I was first diagnosed in Sydney, I linked in to Positive Women but I was terrified of making contact. I don't know why. Maybe once again it was my perception of what these positive people are going to be like. We'd had a lot of bad reactions with the AIDS Council. They'd always assumed that John was gay and I was his dyke flatmate. You know, he was the one who was positive and all this sort of stuff. So I guess I expected the same thing from Positive Women and when we moved I was involved with the Positive Living Centre, for a number of years before I actually made contact with Positive Women.

So I sort of wonder the amount of women who do the same thing, you know, this assumption that it's really cliquey, god what place isn't cliquey but, you know... but that is my main outlet for my feelings and probably the main place where I can have my feelings validated. But I don't have irrational fears or irrational thoughts about medications and that is the only place that... I mean, sure there's all this research done on men and all the rest of it but, you know, there's so little done on women and even tiny side effects such as, um, oh I can't think of anything at the moment, but Positive Women is the only place where, you know, you can say, oh I had...oh I've got heaps of hair falling out. You know, all these other women are saying, oh shit, so do I. There will be nothing documented but just... you think well shit I'm not alone, someone else is having the same thing, I'm not a sort of hypochondriac or that sort of stuff. So, as I said, to be validated and, this huge...I mean it's even stuff that you can't get from your partner because I guess there's no... it's amazing, we're all so different yet were just drawn together by this same thing and can just share and learn so much from each other. So that's huge. Um, I don't know where I'd be if Positive Women didn't exist

Debbie, 25, diagnosed 1991

3 About the Sample

3.1 Recruitment

A stratified purposive sampling strategy was utilised to sample people living with HIV/AIDS in Australia. The recruitment occurred between 1 July 1997 through 5 September 1997. Recruitment involved distribution of self-administered mail-back questionnaires through HIV/AIDS organisations, a number of mailing lists, and through a targeted advertising campaign. The mailing lists included those of four free publications that provide information about living with HIV/AIDS: *Talkabout* (New South Wales), *PL* (Western Australia), *QPP Alive* (Queensland), and *Positive Living* (Victorian recipients of the national newspaper insert). It is not possible to know what proportion of the recipients of these magazines are HIV-positive, and as a consequence response rates cannot be calculated.

Additional targeted distribution occurred in order to ensure the sample included sufficient numbers to enable statistical comparisons of data from groups which have distinctive issues and experiences and who may not have been contacted through the main distribution channels. These groups included women, people living with Haemophilia, and people living outside of New South Wales and Victoria.

3.2 Sample demographics of women

The survey was completed by 84 women out of a total of 925 respondents: 834 of the remainder were men and seven respondents did not indicate their sex. The whole sample represents 8.3% of the current population of people living with HIV/AIDS in Australia as estimated by the *Australian HIV Surveillance Report* (NCHECR 1997). The 84 women represent 13% of the total estimated number of women living with HIV/AIDS in Australia.

Female respondents' ages ranged from 23 to 71 years (median = 34.0 years, mean = 35.9 years). Women's ages at the time of diagnosis with HIV ranged from 14 to 61 years (median = 29.0 years, mean = 29.8 years). The average length of time since women first tested HIV-positive was 6.1 years. Slightly more than half of the women have been HIV-positive for 5 or more years, and more than one-third have been HIV-positive for less than 5 years. Less than one-fifth have been HIV-positive for 10 years or more.

Of the 84 women who completed the survey, 82% said they are heterosexual, 10% are lesbian/gay and 6% are bisexual. Only two women (2%) did not indicate their sexual orientation.

Respondents were asked to indicate how they believe they were infected with HIV. Table 1 presents the results for women, grouped into the categories used by the National Centre in HIV Epidemiology and Clinical Research in the Australian HIV Surveillance Report.

Table 1 Mode of transmission of HIV

Perceived mode of transmission	n	%
Heterosexual contact (sex with a man)	51	(61%)
Injecting drug use	15	(18%)
Receipt of blood components/tissue	9	(11%)
Injecting and heterosexual contact	2	(2%)
Health care setting	2	(2%)
Homosexual contact (sex with a woman)	1	(1%)
Don't know	4	(5%)

n = 84

Of the 84 women who completed the survey 27 (32%) reside in Victoria, 26 (31%) in New South Wales, 9 (11%) in Queensland, 7 (8%) in Western Australia, 6 (7%) in South Australia, 3 (4%) in the Australian Capital Territory and 1 (1%) in the Northern Territory. Five women (6%) did not indicate in which State they live.

Most women (56%) live in the inner suburbs of capital cities, while 23% live in outer suburban areas, 12% live in a regional centre, 9% live in a rural area.

Two-thirds (66%) of women identify their ethnic/racial background as Anglo-Australian. The most frequently cited other ethnic/racial background was European (11%), with 5% citing an Aboriginal/Torres Strait Islander background, and 5% citing an Asian background.

Half (50%) of the female respondents said they have dependent children. More than a quarter (29%) said they have one dependent child, 14% reported that they have two dependent children, 6% reported having three dependent children and 1% reported having 4 dependent children.

Generally, women reported high levels of education. Almost one-third (31%) have completed a university degree and 11% have completed a tertiary diploma or TAFE education. A further 28% have completed secondary education, 29% have completed some secondary education, and 1% had completed primary school.

One-fifth (20%) of the women who completed the survey said they have no religious beliefs or that they are atheists. A further 6% said that they are agnostic. Half profess Christian beliefs. Of those women, 21% are Catholic, 10% are Anglican/Church of England, and 19% have other Christian beliefs. Eight per cent of the women have new age religious beliefs, and 9% are Buddhist. More than one-quarter of the sample profess some religious belief, and slightly more than half attend religious meetings. Forty per cent of women do not attend religious meetings, while 19% attend less than once a year, 25% attend at least once a year, 10% attend at least once a month, and 7% attend religious meetings at least once a week.

3.3 Representativeness of the sample

To assess the degree to which the sample recruited for this study is representative of all PLWHA in Australia, comparisons were made with the *Australian HIV Surveillance Report* (NCHECR, 1997). As a consequence of the deliberate sampling strategy to include larger numbers of marginalised groups, the Futures survey under-represents PLWHA from New South Wales. The survey over-represents women, people who have had an AIDS-defining illness, and people infected through: receipt of blood products; haemophilia/coagulation disorder and in health care settings.

The results reported in the remainder of the report below are weighted to take account of the over-representation of women, the under-representation of PLWHA from NSW, and the over-representation of people with medically acquired HIV and people with AIDS. The data were weighted to take into account the differences in demographic data reported in the *Australian HIV Surveillance Report* (NCHECR, 1997).

A range of statistical comparisons are made in this report. For clarity, the results of these analyses (χ^2 -tests, t-tests, ANOVA, and logistic regression) are not reported in this report. All significant differences reported are significant at $p < .05$.

...the way I was told, over the phone, I mean that's all just absolute crap. He could have got me into his office that day a million times. He could have said any single thing. He did not have to tell me over the phone. He could have just said look I need to speak to you, I'm not prepared to discuss it over the phone, it is urgent and I do need to see you today. Well look I was busy, I was stressed out at work but I still would have, the curiosity side, I would have gone. But I had to be driven home that day because I burst into tears. And I went into the office manager and said I have to go. And I was crying. And he said well we can't let you go, you've got to drive an hour home. And drove me home. And I cried all the way home saying I can't believe it, I can't believe it. And so it led me then to have to tell work. Because I was a fucking' mess. I, that could have been completely avoided. There was no need for that.

There's a lot of ways you can get people into a doctor's surgery. He could have rung me at home that night and said to me look can you come into the surgery first thing in the morning. He could have told me at home at night. He could have rung out and found out there's no way it's a mistake. He could have found out the results, rung the AIDS line, got the information, said "How do I do this?", but doctors think they're above it. They couldn't possibly ring the AIDS line or anywhere that gives them information. Because he's done a course, three years ago. And he knew about it. But it still didn't help him handle it. So, probably in that way, any respect that I had for doctors, where you think what they tell you is the right thing and you just do what they say, now I question what they say and I ask them questions - lots of them. And I decide what I'm going to do or what I'm not going to do. I take their advice and then I find out about it.

Sarah, 36, diagnosed 1994

4 Health Status and Health Management

Key findings

Most women who completed this survey have taken both a CD4/T-cell and viral load test. This includes those women who are not currently using anti-viral treatments.

Almost one-quarter of the women rate their health as being excellent or good. Fewer than one-third of women reported that they have Hepatitis C. A range of other health conditions were also reported such as psychological or psychiatric conditions, cardiovascular disease and hypertension.

Although more than half of the women think that their doctors are more knowledgeable than themselves about treatments for HIV/AIDS, the vast majority of women reported that they work together with their doctor in their decision-making around treatments. This supports the reputation Australian PLWHA have for being pro-active and involved in the management of their own health.

Women were quite divided on when they think PLWHA should begin anti-viral treatments. Almost one-quarter of women either disagree or are unsure when asked whether PLWHA should begin anti-viral treatment as soon as possible.

4.1 Health status of women

4.1.1 *What do women know about their CD4 and viral load counts?*

Nearly all of the women who completed the survey (99%) have taken a CD4/T-Cell test. The results of women's most recent CD4/T-Cell tests ranged from 10 to 1011 cells/mL (median = 446 cells/mL, mean = 420 cells/mL). Among the women who have taken a CD4/T-Cell test, 78% reported that at some time in the past they have had a CD4 /T-Cell count below 400 cells/mL, and 44% reported that at some time in the past they have had a CD4 /T-Cell count below 200 cells/mL.

The number of women who have taken a viral load test was also high (92%). The results of women's most recent viral load tests ranged from an undetectable level to 780,000 copies/mL (median = 1,272 copies/mL, mean = 47,359 copies/mL).

Table 2 Serological testing

Test	copies/mL blood	n	%
CD4/T cells			
little/no immune system damage	more than 500	24	(33%)
moderate immune system damage	250 - 500	31	(42%)
severe immune system damage	less than 250	19	(25%)
Viral load			
below detectable level	less than 500	26	(40%)
low	500 - 10,000	17	(26%)
moderate	10,000 - 50,000	9	(15%)
high	more than 50,000	12	(19%)

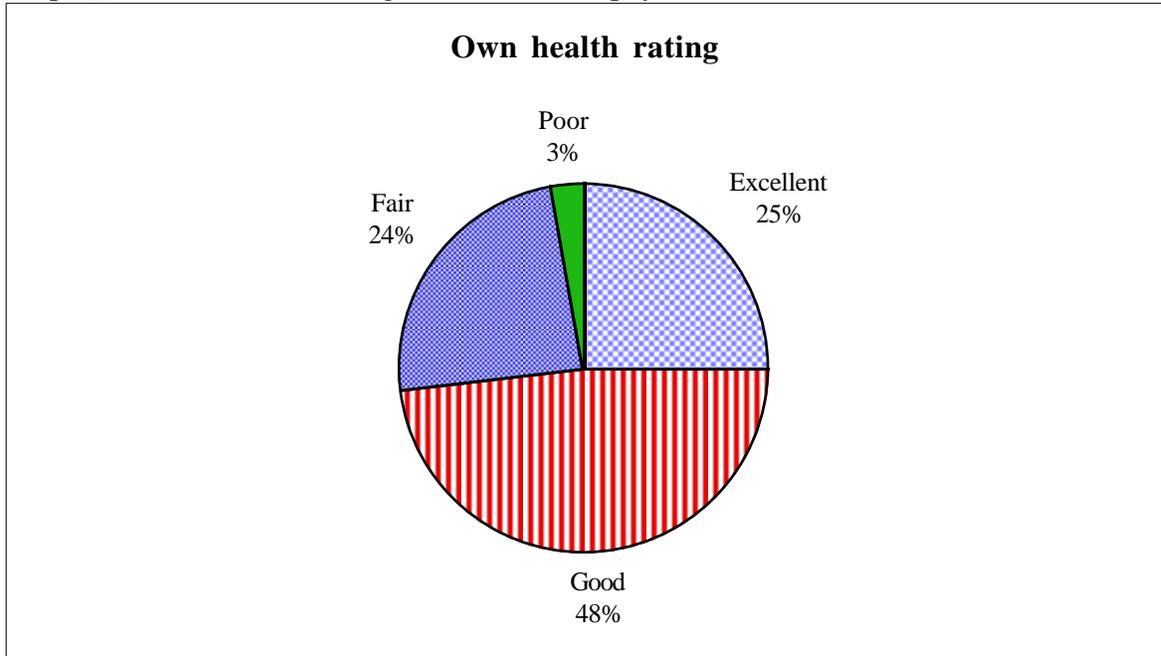
1 - n = 74 for CD4/T-cell test; n = 64 for viral load test

The six women in the study who have not taken a viral load test gave the following reasons for not having done so: *I don't believe that I need one* (2); *I'm scared of the results* (2); *I haven't gotten around to it* (1); and *I thought they were expensive* (1). There was no difference between men and women in terms of the results of their CD4/T cells or viral load counts.

4.1.2 How do women rate their own health?

Many women reported that their current state of physical health is good or excellent. There were no significant differences between men and women and how they rate their health nor were there any significant differences between those women who had been diagnosed with an AIDS-defining illness and those women who had not. In contrast to a recent American study (Richter et al., 1998), no relationship was found between current health and use of anti-virals.

Graph 1 Women's ratings of their current physical health



n = 79

4.1.3 What major health conditions other than HIV/AIDS do women report?

Slightly fewer than one-third (30%) of the women living with HIV/AIDS who completed the survey reported that they have at least one major health condition other than HIV/AIDS. Of those with another major health condition the most commonly cited was Hepatitis C (31%). Other commonly cited health conditions included cardiovascular disease (4 women), hypertension (3 women), and psychological/psychiatric conditions (2 women). Uterine bleeding, Asthma, back injury/back pain, Peripheral Neuropathy, Diabetes, kidney disease, cancer (non-Karposi Sarcoma), Mycobacterium Avium Complex, Wilson's disease and Thallassemia were also reported . There was no association between diagnosis with an AIDS-defining illness and reporting any major health conditions other than HIV/AIDS.

Of the women who completed the survey, 6% reported that they have been diagnosed with Hepatitis A, and 14% reported that they have been diagnosed with Hepatitis B. The majority of women (73%) reported that they have been tested for Hepatitis C. Among those who have been tested, 50% tested negative for Hepatitis C, 43% tested positive for Hepatitis C, and 7% do not know the result of their test.

4.2 Attitudes towards health management

Respondents were asked a series of questions which assessed their attitudes toward treatments for HIV/AIDS other than anti-viral drugs, and health management in general. Their responses are displayed in Table 3. Nearly all (99%) women agree that *Keeping an optimistic frame of mind is an important part of managing my HIV infection*, and 97% agree that *Looking after my physical fitness is an important part of managing my HIV infection*. It is interesting to note that although the majority (58%) of women think that their doctor knows a lot more than them about treatments for HIV/AIDS, most women (89%) who completed the survey reported that they work together with their doctor to determine the best treatment regime for them. Women seemed to be divided on the issue of when PLWHA should begin using anti-viral drugs. Fewer than one-third (27%) agree that PLWHA should begin anti-viral therapy as soon as possible, more than one-third (38%) disagree, with the remainder (35%) unsure as to whether early intervention is desirable.

Table 3 Attitudes toward health management

Attitude statement	disagree		agree		don't know	
	n	%	n	%	n	%
As long as I am well I prefer not to think about HIV/AIDS	43	(55%)	34	(43%)	2	(2%)
My doctor knows a lot more about the treatment of HIV than I do	29	(37%)	45	(58%)	4	(5%)
I like to find out as much as I can about the medical studies of HIV	8	(10%)	68	(88%)	2	(3%)
Looking after my physical fitness is an important part of managing my HIV infection	0	(0%)	76	(98%)	3	(3%)
Keeping an optimistic frame of mind is an important part of managing my HIV infection	0	(0%)	78	(99%)	1	(1%)
My doctor and I work together to find the best treatment for me	6	(8%)	70	(89%)	2	(3%)
People with HIV should start using anti-viral drugs as soon as possible	29	(38%)	21	(27%)	26	(35%)

n = 74 - 79 n varies from item to item due to missing data

A significant relationship was found between certain attitudes toward health management and whether or not women are using anti-viral drugs. Compared to women who are not using anti-virals, women who were using anti-virals are significantly more likely to agree that:

- they work together with their doctor to find the best treatment; and
- people with HIV should start using anti-viral drugs as soon as possible .

The last result echoes the results of a study of American PLWHA (Richter et al. 1998) which revealed that PLWHA with more favourable attitudes toward anti-virals were significantly more likely to be using these drugs than PLWHA with less favourable attitudes.

I mean AZT was hailed as the wonder drug when it first came out and these are all being part of these wonder drugs and they're terrific. They are, they're working for a great proportion of people. But there are some people, number one, that they're not working for and number two, there are some people that have had terrible side effects. I don't like interventionist sort of medicine anyway. And I know that's really a shocking thing to say, but I've thought a lot about death and dying and I don't know if intervention is... I mean sure, there's no question that if somebody says to me take these pills they'll help you, I mean at this stage I'm not going to say no. But I can see a time when I would refuse treatment.

Belinda, 42, diagnosed 1991

I'm not quickly jumping on 'it's just a chronic illness now bandwagon', especially since Protease Inhibitors are just starting to look at the nasty side affects like, that lately and that kind of stuff that nobody expected, that it was coming up and, and they can really make you feel like shit, and it's really hard to comply all the time and if you have an active lifestyle and I'm - I mean I have pretty - the kind of lifestyle I've always wanted to lead, and do lead, is very active and I want to be able to do that with my life and if I can't do that then I get really pissed off and taking that treatment really impinges on that, at least at the moment it does. So I guess for me at the moment, even though it may prolong my life, still may not, I mean it's really unknown, it's a really grey area at the moment and all the sequencing of drugs and resistance, it all varies between individuals so much and for some people it doesn't work at all. I guess seeing all that kind of stuff has made me think twice about it - a bit more hesitant about jumping on and taking you know, whatever's handed to me at the time.

Arlene, 26, diagnosed 1990

Key findings

A significantly smaller proportion of women than men reported that they use anti-viral treatments. However, of those women who are not using anti-viral treatments most reported that their health does not warrant it.

Almost two-thirds of women using anti-viral drugs reported that they experience side-effects. The majority of these women also reported that they experience difficulties in taking their medication, which included remembering to take their medication on time or having to adapt sleep patterns to the treatment regime and organising meals around medications.

The significance of the relationship women have with their doctors is revealed in the finding that the vast majority of women using anti-viral drugs decided to do so on advice from their doctor.

One-quarter of the women who are not using anti-viral drugs reported having done so in the past. The most commonly cited reason for discontinuing use was the severity of the side-effects. The majority of women not using anti-viral treatment said they would do so in the future if their health declined. Also cited as an influencing factor in the decision for anti-viral uptake is the belief in the efficacy and/or safety of the treatments.

There was a significant difference between men and women in the belief that new treatments have brought hope and better prospects for PLWHA. Men were significantly more likely than women to report that combination anti-viral treatments mean better prospects for most PLWHA. This difference is highlighted by the finding that one-third of women reporting that they believe anti-viral drugs are harmful. At the same time, more than two-thirds of women expressed a belief that new anti-viral drugs will be developed in time for them to gain benefits.

Two-thirds of the women reported using complementary therapies. More than half use vitamin or mineral supplements, one-third use massage, and about a quarter used herbal therapies or meditation.

5.1 About women who are using anti-viral treatments

5.1.1 How many women are using anti-viral drugs?

Less than two-thirds (61%) of the women who completed the survey are using anti-viral drugs for HIV/AIDS. This figure is significantly lower than the figure for the men who completed the survey (79%).

Among the women who are using anti-viral drugs, 19% are using two anti-viral drugs, and 81% are using three or more anti-viral drugs. None of the women in the survey who reported using anti-viral drugs are on monotherapy (one anti-viral drug).

The AFAO guide *HIV Tests and Treatments* (1997) recommends starting or changing combination therapy for PLWHA who have:

- a viral load more than 10,000 copies/mL blood and a declining CD4 count; or
- a viral load more than 50,000 copies/mL blood regardless of CD4 count.

Thirty-nine per cent of the women are not using anti-viral treatments. By using the women's reports of their most recent viral load test result and their CD4 test results during the 12 months prior to completing the survey, it was possible to determine the proportion of women who should be using anti-viral therapy according to the AFAO guide. Of the 30 women in the survey who were not using anti-virals, only five should be using anti-virals given their reported CD4 and viral load results.

5.1.3 Are these data reliable?

More than half (61%) of the women who completed the survey are using combination anti-viral drugs for HIV/AIDS. However, because the survey was distributed through both PLWHA organisations and medical services, women living with HIV/AIDS who have no contact with either PLWHA organisations or medical services may be under-represented. In the absence of any external data on the proportion of women with no contact with either PLWHA organisations or medical services, it can be assumed that the figure of 61% of women using two or more anti-viral drugs in combination in this survey is a high estimate of the proportion of all women using two or more anti-viral drugs in combination in Australia.

Other information on this question is available, for example from nationally collated pharmacy data on the prescription of anti-viral drugs. These information sources indicate that at least 60% of PLWHA (men and women) in Australia who know their HIV-positive status are using anti-virals. This data is not available separately for men and women.

5.1.4 Are viral load or CD4 counts different among women using anti-viral drugs and women not using anti-viral drugs?

Women who have been diagnosed with an AIDS-defining illness are no more likely to be using anti-viral drugs for HIV/AIDS than those who have not been diagnosed with AIDS. Use of anti-viral drugs is also related to the results of serological testing. A significant relationship was found between use of anti-viral drugs for HIV/AIDS and CD4/T-cell count. Compared to women who are not using anti-viral drugs for HIV/AIDS, women who are using anti-viral drugs are significantly more likely to report severe immune damage (CD4/T-cell count less than 250 copies/mL). The proportion of women using anti-viral drugs was the same for those women who reported undetectable viral loads, and those women who reported moderate or high viral loads.

Table 4 displays women's reports of the results of their most recent CD4/T-cell test and their most recent viral load test.

Table 4 Relationship between serological test results and use of anti-viral drugs

Test	Copies/mL	Using anti-virals			
		yes		no	
		n	%	n	%
CD4/T cells¹					
little / no immune system damage	more than 500	11	(24%)	13	(48%)
moderate immune system damage	250 - 500	18	(39%)	13	(45%)
severe immune system damage	less than 250	17	(37%)	2	(7%)
viral load²					
below detectable level	less than 500	19	(47%)	7	(30%)
low	500 - 10,000	11	(25%)	6	(26%)
moderate	10,000 - 50,000	4	(10%)	5	(23%)
high	more than 50,000	7	(18%)	5	(21%)

1 - n = 74 for CD4/T-cell test

2 - n = 64 for viral load test

5.1.5 What side-effects are experienced?

As can be seen in Table 5, almost two-thirds (63%) of the women who are using anti-viral drugs for HIV/AIDS reported that they experience side-effects. Almost half (46%) of all women who are using anti-viral drugs experience nausea, and one-fifth (20%) experience diarrhoea, headaches, fatigue and vomiting.

Table 5 Side effects and difficulties in taking anti-viral medication

Difficulties	n	%	n	%
Side effects of anti-viral drugs			30	(63%)
nausea	14	(46%)		
fatigue / lethargy	10	(33%)		
headaches	7	(24%)		
diarrhoea	6	(20%)		
vomiting	6	(20%)		
skin dryness / rashes / itchiness	5	(15%)		
metallic taste / tingling / numbness in mouth	4	(13%)		
dizziness, blurred vision, etc.	4	(13%)		
weight fluctuation	4	(13%)		
insomnia	3	(10%)		
pain (joint and/or muscle)	3	(10%)		
bloated stomach	3	(10%)		
hair loss	2	(6%)		
neuropathy	2	(6%)		
gastric reflux/indigestion	2	(6%)		
flatulence	1	(3%)		
mood swings / irritability	1	(3%)		
change in menstrual cycle	1	(3%)		
Anti-viral drugs conflict with other medication			1	(3%)

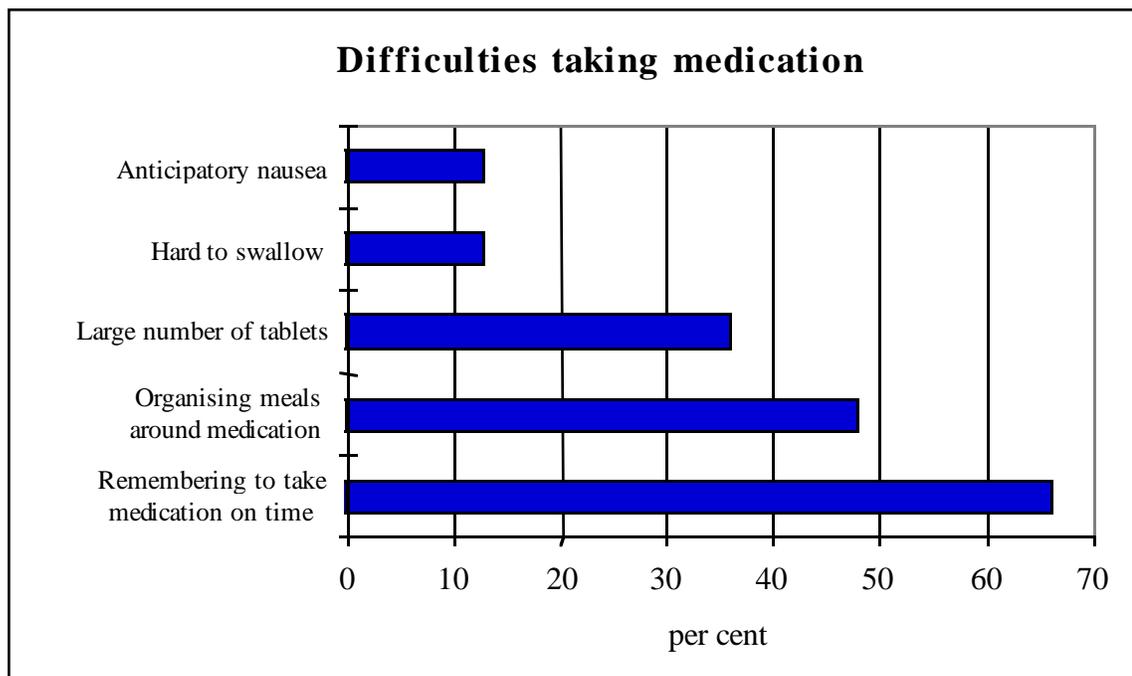
Multiple responses possible

Proportion of those who are using anti-viral drugs, n = 48

5.1.6 What difficulties do women have using anti-viral treatments?

The majority of women (91%) who are using anti-viral drugs reported that they experience difficulties in taking this medication. Graph 2 shows that two-thirds (66%) of the women who are using anti-virals have difficulties remembering to take their medication on time or having to adapt normal sleep patterns to the treatment regime, and that half (48%) have difficulties organising their meals around medication (eg, fasting before taking medication). More than one-third (38%) of the women also reported that they have difficulty taking these drugs in public because they do not want people to know their HIV status. When taken with the finding that 36% of women using anti-virals reported that they have difficulties taking large numbers of tablets, the results reported above have potentially serious implications for long-term compliance with treatment regimes unless less complicated and burdensome treatment regimes can be developed.

Graph 2 Difficulties experienced by women taking medication



n = 49 Proportion of all women using anti-viral drugs

Women who have been diagnosed with an AIDS-defining illness are just as likely as other women to report that: they experience side-effects from anti-viral drugs; they have difficulties taking anti-virals; they have difficulties taking this medication in public; and anti-viral drugs conflict with medication taken for other health conditions. There was no significant difference between the proportion of men and women who are using anti-viral drugs for HIV/AIDS who reported side-effects, difficulties taking medication, difficulties taking medication in public, or conflict with medication for other health conditions.

5.1.7 How long have women been using anti-viral drugs?

The 61% of women who are using combination therapy or conventional medical therapy have been doing so for periods ranging from one month to eight years. However, the median time for which women have used combination therapy is 18 months (mean = 30 months). This suggests that the majority of women using more than one anti-viral drug had started combination therapy after the advent of new treatments, in particular, protease inhibitors.

5.2 About women who are using combination anti-viral treatments

5.2.1 What were women's viral load and CD4 counts when they began combination anti-viral treatment?

Table 6 displays the viral loads and CD4/T-cell counts of women just before they started combination therapy. The data in the table suggest that few women begin combination therapy with high CD4/T-cell counts and/or viral loads below the detectable level as more than half of the women (53%) had CD4/T-cell counts indicating severe immune system damage, and two fifths (39%) had viral loads categorised as high. Once again there was no difference between men and women in terms of their viral loads and CD4/T-cell counts just before they started combination therapy.

Table 6 Serological test results just prior to commencing combination therapy

Test	copies/mL	n	%
CD4/T cells			
little / no damage	more than 500	2	(4%)
moderate damage	250 - 500	18	(43%)
severe damage	less than 250	22	(53%)
Viral load			
test not available	-	13	(32%)
below detection	less than 500	1	(2%)
low	500 - 10,000	5	(11%)
moderate	10,000 - 50,000	6	(16%)
high	more than 50,000	16	(39%)

n = 42 for CD4/T-cell test, n = 40 for viral load test

5.2.2 How do women rate their health and well-being since beginning combination anti-viral treatment?

Women were divided as to how they perceive their physical health since they started on combination therapy. Slightly more than one-third (36%) of the women using anti-viral drugs reported that their physical health has improved since they started combination therapy, 32% reported no change in their physical health, 31% reported that their physical health has fluctuated, and 1% reported a deterioration in their physical health.

Similarly, 37% of the women using anti-viral drugs reported an improvement in their overall feeling of well-being since starting combination therapy, while 30% reported that their overall feeling of well-being has fluctuated. There was no reported change in their overall feeling of well-being for 27% of women, and 6% reported a deterioration in their overall feeling of well-being.

Women were no more or less likely than men to report that their physical health or overall feeling of well-being had fluctuated or deteriorated.

5.2.3 *What happened just prior to beginning combination anti-viral treatment?*

Participants who are using combination anti-viral drugs were asked to describe the events which occurred just prior to their commencement of combination therapy. Women's responses are displayed in Table 7. The influence of the advice of doctors on people's decisions to commence combination therapy is evident - 86% reported that their doctor advised them to. However, it is also important to note that more than one-third (35%) of the women reported that their decision to commence combination therapy was preceded by a personal decision that combination therapy is effective.

Table 7 Events occurring prior to commencing combination anti-viral therapy

Event	n	%
My doctor advised me to begin this treatment	41	(86%)
I had a significant drop in my CD4/T-cell count	21	(44%)
I decided that combination therapy is an effective treatment for HIV	17	(35%)
I became very ill	10	(21%)
I had a significant rise in my viral load	9	(19%)
I began to see a doctor or was hospitalised due to HIV-related infections	8	(17%)
A number of my positive friends began to take up combination therapy	7	(15%)
Enrolled in a trial	3	(6%)

n = 48 Multiple response possible

5.3 **About women who are not using anti-viral treatments**

5.3.1 *How many women have used anti-viral treatments in the past?*

Eight of the 31 women who are not using anti-viral drugs for HIV/AIDS have used these drugs in the past. Of these women, four used one anti-viral drug, one used two anti-viral drugs, and two had used three or more anti-viral drugs (one did not specify).

5.3.2 *Why did women stop using anti-viral treatments?*

The reasons these women gave for discontinuing use of anti-viral drugs are shown in Table 8. It is interesting to note the importance of side-effects of anti-viral drugs for HIV/AIDS. As noted earlier, slightly fewer than two-thirds of women using these drugs reported side-effects, and many have difficulties remembering to take drugs on time, spacing meals around medication and/or taking large numbers of pills. As shown in Table 8, among women who are not using anti-viral drugs but who have used them in the past, the most commonly cited reasons for ceasing use were severe side-effects and onset of neuropathy (another side-effect).

Women who had used anti-virals in the past but were not using them at the time of completing the survey had used them for periods ranging from one month to two and a half years, with a mean of 15 months and a median of 15 months. The length of time since women had used these drugs ranged from two weeks to eight years (median = 38 months, mean = 36 months).

Table 8 Reasons given for discontinuing use of anti-viral drugs given by women who have used these treatments in the past

Reason for discontinuing use	n	%	n	%
Onset of neuropathy			4	(50%)
Side effects became too severe			7	(88%)
They were not working for me			6	(75%)
as indicated by CD4 and/or viral load tests	4	(50%)		
only took during pregnancy	1	(13%)		
quantity of drugs a became a burden	1	(13%)		
Taking drugs at the right time became too difficult			2	(25%)

n = 8 Multiple response possible

5.3.3 *What would prompt these women to recommence anti-viral treatments?*

The majority (83%) of women who are not using anti-viral drugs said that they would consider using these drugs at some time in the future. The answers women gave when asked why they would take up anti-viral treatments are displayed in Table 9. The most commonly cited reasons are related to markers of declining physical health (eg, opportunistic infection, results of serological testing), but it is interesting to note that many women reported that their decision to commence use of anti-viral drugs is influenced by a belief in the efficacy and/or safety of these treatments.

Table 9 Reasons given for considering commencing use of anti-viral drugs in the future

Reason for considering anti-viral drugs	n	%
If I had a big drop in my overall health	20	(67%)
If I had a big drop in my CD4/T-cell count	17	(57%)
If I had a big rise in my viral load	17	(57%)
If I was certain that anti-viral treatment was an effective treatment for HIV	16	(53%)
If the drugs were shown to be safe in the long term	16	(53%)
If I developed an opportunistic infection	15	(50%)
If a doctor recommended that I take up treatments	9	(30%)
If new drugs became available	4	(13%)
If my positive friends recommended that I take up treatments	2	(6%)

n = 30 Multiple response possible

5.4 Attitudes towards anti-viral treatments (all women)

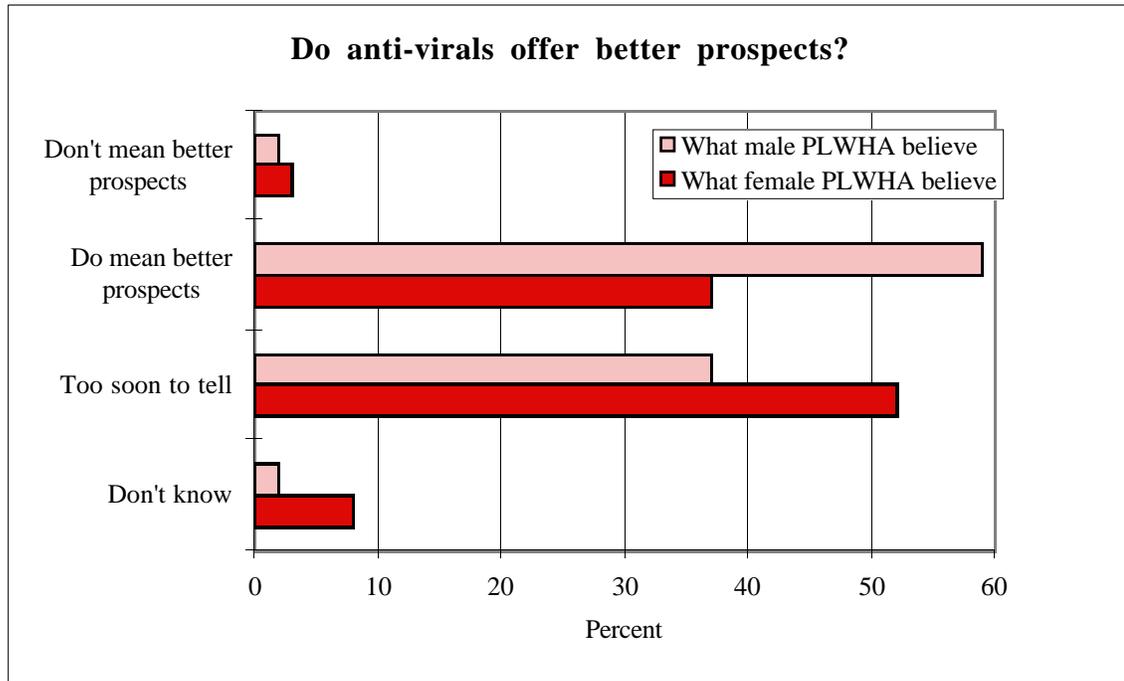
5.4.1 *What do women believe others are saying about new anti-viral treatments and what do they think themselves?*

Respondents were asked whether they think that combination anti-viral drugs mean better prospects for most people with HIV/AIDS and whether they think that other people believe that combination anti-viral drugs mean better prospects for most people with HIV/AIDS.

Slightly more than one-third of the women (37%) believe that combination anti-viral drugs mean better prospects for most PLWHA, while 51% say that it is too soon to tell, 8% don't know, and 3% do not believe that they mean better prospects. The data also reveal that most women (62%) think that other people believe combination anti-virals mean better prospects, while 14% think that others think it is too soon to tell, 22% do not know what others think, and 3% think that other people do not believe that combination anti-virals mean better prospects. In other words, women as individuals are more cautious about the impact of treatments than they believe PLWHA in general are.

There was a significant difference in the way female and male PLWHA view anti-viral drugs as meaning better prospects. As seen in Graph 3, men are significantly more likely than women to believe that combination anti-viral drugs mean better prospects for most PLWHA (59% vs 37%) and women were significantly more likely to say they do not think combination anti-viral drugs mean better prospects for most PLWHA or that it was too soon to tell or they did not know (63% vs 41%).

Graph 3 Do PLWHA believe that anti-virals offer better prospects?



n = 877

5.5 Attitudes towards combination anti-viral treatments

A series of questions assessed respondents’ attitudes toward combination anti-viral drugs. The responses given by women are displayed in Table 10. One-third (33%) of women believe that combination anti-viral drugs are harmful, and slightly more than one-third (35%) do not. Thirty-two per cent of women gave a don’t know response to this statement. Whilst 44% of women said that they don’t need combination anti-viral drugs, when asked whether they believe anti-viral drugs are ineffective 71% disagree.

The overall impression given by the data in Table 10 is that women have mixed feelings about anti-viral drugs in relation to them being harmful and whether or not they improve their quality of life. Most women do believe that they have easy access to combination anti-viral drugs, and that combination anti-viral drugs are effective.

Table 10 Attitudes toward combination anti-viral drugs

Attitude statement	Disagree		Agree		Don't know	
	n	%	n	%	n	%
I am healthy now and don't need to use combination anti-viral drugs	40	(51%)	35	(44%)	4	(5%)
I believe combination anti-viral drugs are harmful	28	(35%)	26	(33%)	25	(32%)
I believe combination anti-viral drugs are ineffective	55	(71%)	4	(5%)	19	(25%)
Combination anti-viral drugs have allowed me to plan my life with confidence for the long term [†]	13	(24%)	32	(59%)	10	(17%)
It is easy for me to get combination anti-viral drugs	6	(7%)	62	(82%)	9	(12%)
I have had previous bad experiences with combination anti-viral drugs [†]	27	(48%)	24	(44%)	4	(8%)
Combination anti-viral drugs have made my life better [†]	20	(27%)	33	(44%)	21	(29%)

n = 55 - 79 n varies from item to item due to missing values

† only includes responses by those who have used anti-viral drugs

A number of significant associations were found between use of combination anti-viral drugs and attitudes toward combination anti-viral drugs. Compared to women who are not using anti-viral drugs, women who are using anti-viral drugs are significantly more likely to disagree that:

- they do not need to use combination anti-virals due to current good health;
- combination anti-viral drugs are harmful; and
- combination anti-viral drugs are ineffective.

Women using anti-viral drugs are also more likely than those not using anti-viral drugs to agree that:

- combination anti-viral drugs have allowed them to plan their life with confidence for the long term
- it is easy for them to get combination anti-viral drugs; and
- combination anti-viral drugs have made their lives better.

A number of significant differences were also found between men and women in relation to their attitudes toward combination anti-viral drugs. Compared to men, women are significantly more likely to agree that:

- they do not need to use combination anti-virals due to current good health.
- combination anti-viral drugs are harmful; and
- combination anti-viral drugs are ineffective.

Compared to men, women are significantly more likely to disagree that:

- combination anti-viral drugs have made my life better.

5.6.1 Attitudes towards anti-viral treatments (among women currently using them)

Women who are using anti-viral treatments were asked to respond to a number of attitude statements about these treatments. Their responses are displayed in Table 11.

The first row of the table highlights the fact that while many women (36%) believe that anti-viral drugs can restore their immune system, slightly more (42%) do not believe that this is possible, while nearly one-quarter (22%) do not know whether this is possible. In addition, many women are worried about the long-term efficacy of current medication for HIV/AIDS. Nevertheless, the majority (70%) of women expressed a belief that new anti-viral drugs will be developed in time for them to gain benefits, although one-quarter (26%) do not know whether this will happen.

Table 11 Attitudes toward anti-viral drugs expressed by women using these drugs

Attitude statement	Disagree		Agree		Don't know	
	n	%	n	%	n	%
Anti-virals can't restore my immune system	17	(36%)	20	(42%)	11	(22%)
I am worried that in the future my medication will stop working for me	5	(10%)	40	(82%)	4	(8%)
Taking tablets gives me an unwanted reminder that I have HIV	18	(37%)	29	(60%)	2	(3%)
Using anti-viral therapy makes me confident that I may stay well	8	(16%)	37	(76%)	4	(8%)
I think new treatments will be developed in time for me to gain benefits	2	(4%)	34	(70%)	13	(26%)

n = 48 - 49 n varies from item to item due to missing values

5.6.2 Why are fewer women using anti-virals than men?

Logistic regression analysis shows us which of a number of factors has the greatest influence on use of anti-viral drugs. Separate logistic regression analyses were conducted for men and women. For both men and women the most important factor in determining whether or not they are using anti-virals is their attitudes toward these drugs. Other important factors for men were disease progression (having been diagnosed with an AIDS-defining illness, and having had a CD4/T-cell count below 400 copies/ μ L), and seeing their doctor as an important source of information about treatments. For women, the only important factor, in addition to attitudes towards drugs, was using a longer rather than a shorter time frame when planning for the future. These sex differences indicate that the primary influences on treatments uptake for women was not disease progression, but their attitudes toward treatments and their time frame when planning for the future. The lower uptake of anti-viral drugs by women living with HIV/AIDS in Australia may be attributable to greater uncertainty about the effects of anti-viral drugs on women.

5.7 Prophylaxis for opportunistic infections

5.7.1 *For which opportunistic infections do women use prophylaxis?*

Almost one-third (29%) of women reported that they are currently using treatments to prevent *Pneumocystis Carinii* pneumonia (PCP) (eg, Bactrim, Dapsone, Pentamidine, Pyrimethamine, Fansidar), while 2% do not know if they are using such treatments. Fewer women (22%) are using preventive treatments for opportunistic infections other than PCP (eg, Riboflavin, Acyclovir, Gancyclovir, Fluconazole), while 5% do not know if they were using such treatments. Overall 25% of the women in this study are using prophylaxis for opportunistic infections (ie, prophylaxis to prevent PCP and/or prophylaxis for other opportunistic infections).

Compared to men, women are significantly less likely to be using prophylaxis for PCP (29% vs 47%), and significantly less likely to be using prophylaxis for other opportunistic infections (22% vs 38%). Overall, women are significantly less likely than men to be using any prophylaxis for opportunistic infections (37% vs 56%).

5.8 Use of complementary therapies

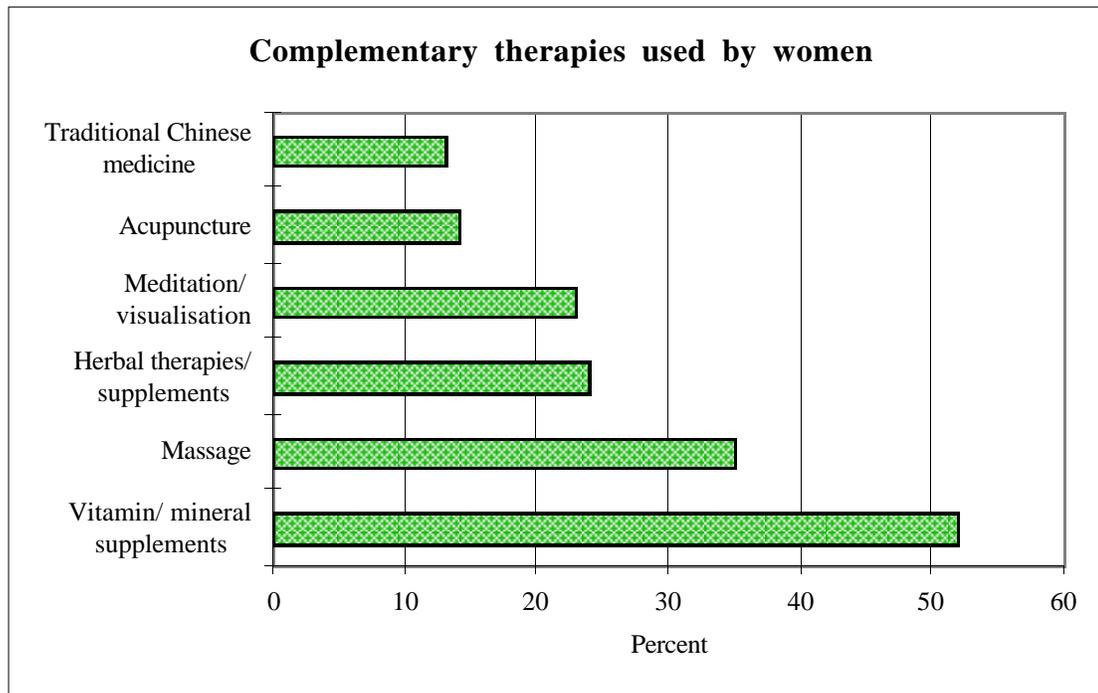
5.8.1 *How many women use complementary therapies?*

Two-thirds (65%) of the women who completed the survey are using complementary therapies. The use of complementary therapies was not related to having been diagnosed with AIDS or the use of anti-viral drugs. Women were no more likely than men to be using complementary therapies for HIV/AIDS.

5.8.2 *Which complementary therapies are most commonly used?*

Graph 4 shows that women reported use of a variety of complementary therapies. The most commonly used complementary therapies are vitamin and mineral supplements, used by nearly half (52%) of all women. Many women also use massage (35%), herbal remedies (24%), and meditation or visualisation (23%).

Graph 4 Complementary therapies used by women



n = 79 (all women) Multiple response possible
Therapies used by less than 10 women not shown in graph

Women who are using complementary therapies reported spending between nothing and \$100 per week on these therapies. Most women, however, spend \$20 or less per week (median = \$15 ; mean = \$22).

5.9 Attitudes towards complementary therapies

In addition to asking PLWHA their beliefs about medical treatments for HIV/AIDS, the survey assessed respondents' attitudes toward complementary/alternative therapies. The responses given by women are displayed in Table 12. More than one-third of women are unsure about some of their beliefs towards complementary therapies which is similar to the number of women who are unsure about combination anti-viral treatment. Nevertheless, there appear to be favourable attitudes toward complementary therapies. The majority (80%) believe that complementary therapies can improve general well-being and over half (60%) of the women believe that use of complementary therapies can delay the onset of HIV-related illnesses. Women also appear to believe that use of complementary/alternative therapies in conjunction with orthodox medical treatments can be beneficial: 58% agree that complementary therapies can reduce the side-effects of conventional medical treatments.

Table 12 Attitudes toward complementary and alternative therapies

Attitude statement	Disagree		Agree		Don't know	
	n	%	n	%	n	%
Complementary therapies can delay the onset of illness due to HIV	1	(1%)	47	(61%)	30	(39%)
Complementary therapies can improve my well-being	2	(2%)	63	(80%)	14	(18%)
Complementary therapies can reduce the side-effects of conventional medical treatments	3	(3%)	46	(58%)	30	(39%)
There is not enough evidence to be sure about the benefits of complementary therapies	36	(46%)	31	(39%)	12	(15%)
Medicine's focus on anti-HIV drugs is very limited	18	(23%)	40	(52%)	19	(25%)
Complementary therapies are a central part of my anti-HIV treatments	28	(36%)	39	(50%)	11	(14%)

n = 77 - 79 n varies from item to item due to missing data

5.10 Using anti-viral treatments, prophylaxis for opportunistic infections, and complementary therapies together

Table 13 summarises the various combinations of orthodox medical therapies and complementary therapies used by women living with HIV/AIDS. Twenty-one per cent of women reported using a combination of anti-viral drugs and complementary therapies and the same number of women are using complementary therapies only. It is interesting to note that 10% of women don't use any treatments at all. Women are significantly more likely than men to report that they only use complementary therapies (21% vs 9%).

Table 13 Patterns of use of anti-viral drugs, prophylaxis for opportunistic infections (OI), and complementary therapies

Treatments used	n	%
Anti-virals and OI prophylaxis and complementary therapies	13	(17%)
Anti-virals and OI prophylaxis	10	(13%)
Anti-virals and complementary therapies	17	(21%)
OI prophylaxis and complementary therapies	4	(5%)
Anti-virals only	8	(10%)
OI prophylaxis only	2	(2%)
Complementary therapies only	17	(21%)
None	8	(10%)

n = 79

But I suppose during that time with Tammy, when things were difficult, we'd have a disagreement not exactly an argument, but disagreements about, for instance, going out. She wanted to go out and she quite social and I'm quite sort of a home person really, so social events aren't - even when I'm well, I'm not over keen on social events, but I go along because, to support her, and it's not that I don't like them, it's just you know, I suppose I'd prefer not to do them, that's all. But there was a particular time when we were going over to a particular friend of hers who, actually he and his wife do actually know about my HIV status, and she'd accepted the invitation to dinner and everything, and I said, "Oh I wonder what time are they going to eat?" and she said, "What do you mean what time are they going to eat?", you know, we very nearly had an argument and I was saying, "Well, you know, I've got to take my pills at this particular time, and I don't know whether I can do it", and she said, "Well you don't have to go then if you don't want to", you know, so it's those kind of difficulties that would occur, and maybe they're just symptoms of the stress more than anything, of an ongoing situation that's always there and you can't ignore it. If you're taking medication you can't ignore it. When I wasn't taking medication I could ignore it and I like to ignore things that's the way I deal with them, but Tammy doesn't, she likes to take it out and look at it and examine it and turn it over.

Jane, 46, diagnosed 1993

I find the issues around HIV become, become so difficult. I think there is an awful lot of ignorance out there in the rest of the world, and as I've said before, I find it very difficult being an educator to somebody. And, in the one relationship that I have had, the one intimate relationship that I have had since I've been positive, I found that they, they would not take responsibility for themselves. I mean, things did fall apart over the issue of being HIV positive. And, and I felt that, that he, he would not take responsibility for finding out things about HIV himself, he expected me to be a resource, like a resource book. Which I felt was unfair on me, because I mean, I don't have all, I didn't have all the answers to his questions. And I wanted him to um, go to an organisation like an AIDS council, but to find out for himself. And he, he chose not to, which was fair enough. But he also chose to listen to friends of his who I consider to be quite ignorant. And although one was a GP, the information that this guy had was quite bizarre, and what I know now to be quite untruthful. So yeah. I felt HIV was a big issue there.

Sally, 33, diagnosed 1994

At first he really didn't want to know about HIV or being involved in any support groups, or meeting any other positive families. But after we had our child I think he's, he realised that we had to start setting up some sort of support network for her if anything did happen to me. So he's become more involved in things, which has been wonderful for me. Because I felt like I was always the one going to things by myself, wanting to know information. But he comes along now, and he's just realised that everyone's just like us, you know. It's not a big deal, there's just some families where one of the partners is positive.

Janelle, 30, diagnosed 1991

6 Relationships and Sex

Key findings

Almost two-thirds of women said they are in a regular relationship or married. Women were most likely to report that they have a monogamous regular relationship. Of those women in a regular relationship, slightly less than two-thirds are in sero-nonconcordant relationships (that is, where their partner is known to be HIV-negative or of unknown HIV status).

Almost all women who are in regular relationships have disclosed their HIV status to their partner. Most frequently, women said that their partners were very supportive in reaction to this disclosure.

Women were divided on their feelings about the impact of new treatments on relationships. Half agree that they are more optimistic about the future than they were a year ago, although almost half disagree. Women were generally less optimistic than men about the future.

Women generally do not agree that HIV/AIDS is a hindrance to developing long-term relationships but half worry about rejection by potential sexual partners in response to the disclosure of their HIV status. Women are significantly more likely than men to say that they worry that nobody would want a relationship with someone who has HIV.

The vast majority of women disagree that the availability of new treatments has made them more confident about having unprotected sex.

With both regular and casual partners, more than half of the women who engaged in sexual intercourse with their partners reported using condoms if their partner is HIV-negative or if they do not know their partner's serostatus.

6.1 Sexual relationships of respondents

6.1.1 *What type of sexual relationships are women having?*

Table 14 displays the kinds of sexual relationships reported by respondents. Because a significant relationship was found between the type of relationship status reported and the respondent's sex and sexual orientation, this table reports on women, heterosexual men and gay/bisexual men. Women were most likely to report that they have a monogamous regular relationship and heterosexual men were most likely to report that they do not have sex at present. Compared to women and heterosexual men, homosexual and bisexual men were

more likely to report that they have a regular relationship with one person and casual sex with other people.

Table 14 Sexual relationships reported by PLWHA

Type of sexual relationship	Women ¹		Hetero- sexual men ²		Gay/ bisexual men ³		Total ⁴	
	n	%	n	%	n	%	n	%
No sex	25	(32%)	21	(38%)	147	(20%)	193	(22%)
Casual sex only	5	(6%)	10	(19%)	231	(32%)	246	(29%)
Regular relationship and casual sex	2	(2%)	4	(7%)	175	(24%)	181	(21%)
Regular relationship only	46	(60%)	19	(35%)	168	(23%)	233	(27%)
Regular relationship with two or more people	0	(0%)	1	(1%)	11	(1%)	12	(1%)

1 - n = 78 2 - n = 55 3 - n = 732 4 - n = 865

6.2 Regular relationships

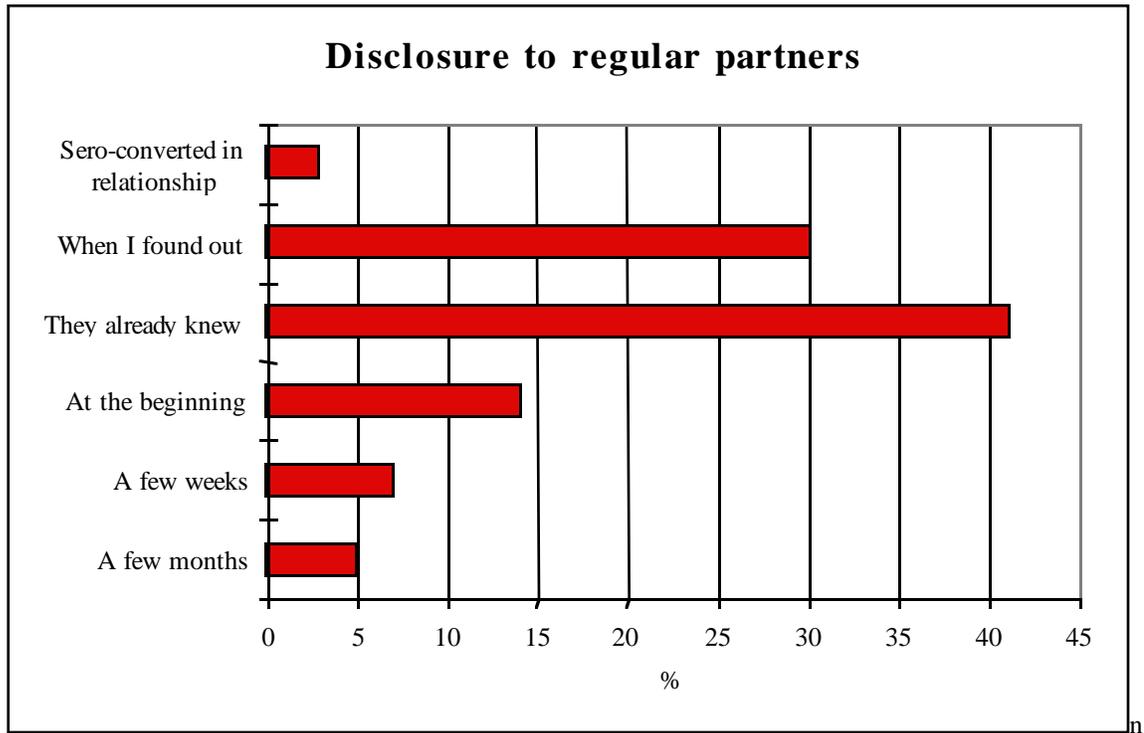
6.2.1 How many women are in regular sexual relationships?

Sixty-four per cent of women said they are in a regular sexual relationship or married. The number of women who reported that they have sex with a regular partner in Table 14 is lower than 64% because not all of the women in regular relationships are sexually active. Of those women who are in a regular relationship, 37% are in seroconcordant relationships (that is, both partners were HIV-positive) and 63% are in sero-nonconcordant relationships (that is one partner is HIV-positive and the other partner is either HIV-negative or their status is not known). This 63% comprises 58% of women who know that their sexual partner is HIV-negative and 5% who do not know their partner's HIV serostatus.

6.2.2 How many women in regular sexual relationships have disclosed their status?

Almost all women (95%) who are in a regular relationship have told their partner that they are HIV-positive. Women were asked to indicate how far into the relationship they told their partner that they were HIV-positive. Their responses are displayed in Graph 5 and indicate that most women told their partner that they are HIV-positive when they tested positive (30%) or at the beginning of the relationship (14%). A further 41% reported that their partner knew that they are HIV-positive before the relationship began.

Graph 5 Disclosure of HIV serostatus to regular partners



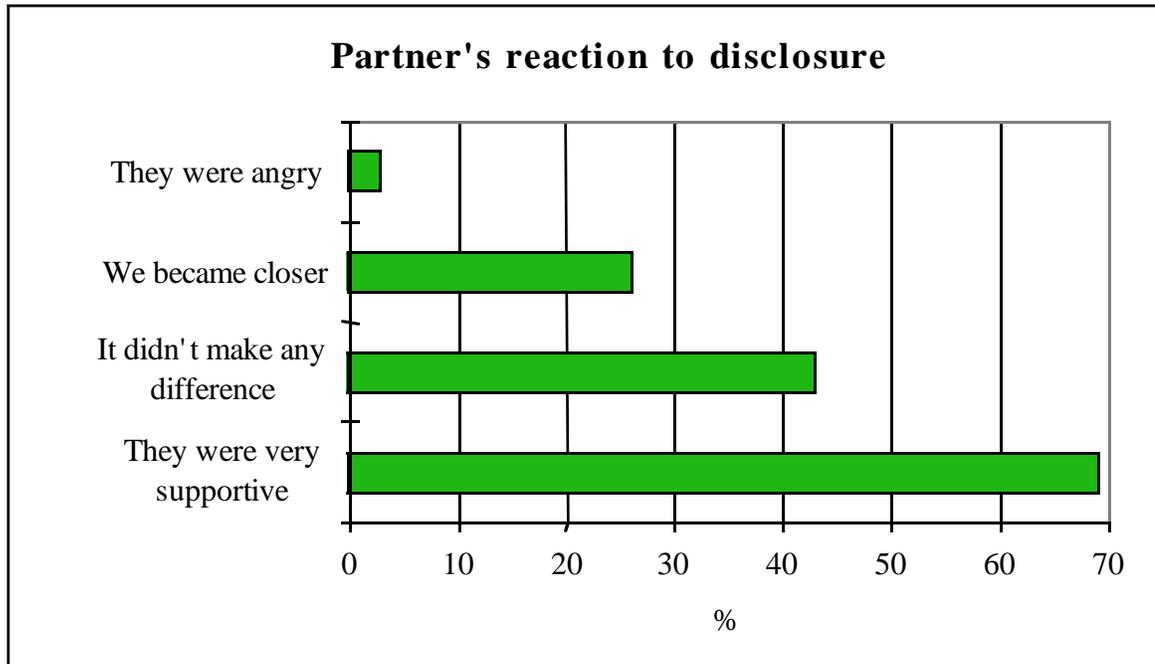
= 48

6.2.3 How did their regular partner react to their disclosure?

Women who have told their partner of their HIV-positive status were asked to indicate how their partner reacted to the disclosure. Their responses are displayed in Graph 6. Most frequently women said that their partners were very supportive (69%). Forty-three per cent reported that it did not make any difference, and 26% said that they became closer to their partner.

Graph 6

Partner's reaction to disclosure of HIV serostatus



n = 47 women who had disclosed their HIV status to their partner
multiple responses possible

6.2.4 What are the impacts of new treatments on the regular relationships of women?

Respondents who were in a regular relationship at the time of completing the survey were asked to express the extent to which they agreed with a number of statements about the impact of the new treatments for HIV/AIDS on their relationship. The responses of women are displayed in Table 15. Overall the impact on relationships of the new treatments environment appears to be quite divided amongst women. Half (50%) of the women reported that they agree with the statement *We are more optimistic about our future than a year ago* and slightly fewer than half (45%) report that they agree with the statement *We now plan our lives together further into the future than we did a year ago*.

Women who are in seroconcordant relationships were significantly more likely to disagree with the statement *We plan our lives together further into the future than we did a year ago* than were men in seroconcordant relationships (62% vs 29%).

Table 15 Regular relationships, optimism and new treatments for HIV/AIDS

Attitude statement	disagree		agree		don't know	
	n	%	n	%	n	%
We now plan our lives together further into the future than we did a year ago	22	(46%)	22	(46%)	4	(8%)
We are more optimistic about our future than a year ago	14	(29%)	24	(50%)	10	(21%)
New HIV treatments are putting a strain on our relationship	34	(69%)	4	(8%)	11	(23%)
We get along much better now there is good news on HIV treatments	23	(49%)	14	(30%)	10	(21%)

n = 47 - 48 proportion of women in a regular relationship

Women were also significantly less likely to agree with the statement *We are more optimistic about our future than a year ago* than were men (50% vs 69%). Women who were in seroconcordant relationships were more likely to disagree with this statement than women who are in sero-nonconcordant relationships (49% vs 18%).

6.3 Attitudes towards relationships and sex

6.3.1 What are the impacts of HIV/AIDS on the sexual relationships of women?

All women were asked to express how they feel about a number of statements about relationships and sex (see Table 16). Women do not appear to believe that having HIV/AIDS would be a hindrance to developing long-term relationships - 66% disagree with the statement *I will never be in long-term relationship because of my HIV status*. However, the majority of women are worried about rejection by potential sexual partners as a response to disclosure of their HIV/AIDS status - 51% of women agree with the statement *I am afraid of telling potential sexual partners of my HIV status in case they reject me* - and many are worried about the risk of transmission of HIV - 71% of women agree with the statement *I am afraid of infecting my partner, or potential partner, with HIV*.

Table 16 Attitudes toward the impact of HIV on relationships

Attitude statement	disagree		agree		don't know	
	n	%	n	%	n	%
I will never be in long-term relationship because of my HIV status	50	(66%)	15	(19%)	11	(15%)
I worry that nobody would want a relationship with someone who has HIV	22	(30%)	48	(64%)	5	(6%)
I am afraid of telling potential sexual partners of my HIV status in case they reject me	30	(39%)	39	(51%)	7	(10%)
I am afraid of infecting my partner, or potential partner, with HIV	17	(24%)	54	(71%)	4	(5%)
I prefer to have a relationship with someone who also has HIV	34	(45%)	20	(27%)	21	(28%)
HIV is not an issue for me in present relationship(s)	33	(45%)	35	(50%)	3	(5%)

n = 72-77 varies due to missing values

6.3.2 Is there any association between personal characteristics of women and their beliefs about the impact of HIV on sexual relationships?

As would be expected, those women who are in a regular sexual relationship or married are significantly more likely than those not in a regular relationship to disagree with the statement *I will never be in a long-term relationship because of my HIV status* (83% vs 35%). There was no difference of opinion between males and females. However, women are significantly more likely to agree with the statement *I worry that nobody would want a relationship with someone who has HIV* than are men (64% vs 46%). Women who are in a regular sexual relationship or married are also significantly more likely than women not in a regular relationship to agree with the statement *HIV is not an issue for me in present relationship(s)* (57% vs 33%).

There was no difference between women in a regular sexual relationship or married and those who are not when women were asked whether they agree with the statement *I am afraid of infecting my partner, or potential partner, with HIV*. Interestingly, women who are taking anti-viral treatments are less likely to disagree with this statement than men who are taking anti-viral treatments (19% vs 29%). Women in sero-nonconcordant relationships were more likely to agree with this statement than were women in seroconcordant relationships (81% vs 53%).

6.4 Attitudes toward treatments and relationships

6.4.1 What are the impacts of new treatments on relationships of women?

To assess the impact of the new anti-viral treatments on attitudes toward relationships, women were asked to think about the new combination treatments in relation to the statements presented in Table 17. The availability of new treatments does not appear to have made women more confident about having unprotected sex. Only 3% of women agree that they feel more confident about unsafe sex as a consequence of the new treatments while 91% disagree and a further 6% do not know. Other impacts of the new treatments environment are less certain. Just over one-third of women (35%) disagree that people with HIV now have a better chance to form relationships. However almost half (47%) disagree that relationships with family and friends are improving due to new treatments, 33% do not know, while only one-fifth (20%) of women agree.

Table 17 Attitudes toward the impact of new anti-viral treatments on sexual relationships

Attitude statement	disagree		agree		don't know	
	n	%	n	%	n	%
I feel more confident about unprotected sex because of the new treatments	70	(91%)	3	(3%)	5	(6%)
People with HIV now have a better chance to form partnerships and relationships	33	(43%)	27	(35%)	17	(22%)
Relationships with friends and family are improving due to the new treatments	36	(47%)	15	(20%)	24	(33%)
Many relationships are breaking up due to the new treatments	37	(49%)	4	(5%)	35	(46%)

n = 75-77 varies due to missing values

6.4.2 How do women compare with men in their attitudes toward the impact of new anti-virals on relationships?

Women and heterosexual men are significantly less likely than homosexual and bisexual men to report that they feel more confident about unprotected sex due to the new treatments than are (3% vs 7%).

Women were significantly less likely to agree with the statement *Relationships with friends and family are improving due to the new treatments* than were men (20% vs 36%).

Homosexual and bisexual men are significantly more likely than women and heterosexual men to agree with the statement *People with HIV now have a better chance to form partnerships and relationships* (54% of homosexual and bisexual men agree, compared to

37% of women and 42% of heterosexual men). The number of lesbians in the sample was too small to allow statistical comparison, but of the six lesbians who answered this question, one agrees, two disagree and three said they don't know.

6.5 Seroconcordant versus sero-nonconcordant relationships

6.5.1 Do women have a preference for seroconcordant relationships?

There is a significant difference between men and women in terms of their preference for a seroconcordant relationship. Women are significantly more likely to disagree with the statement *I prefer to have a relationship with someone who also has HIV* (27% vs 56%).

Table 18 Preference for a relationship with another PLWHA

	Agree		Disagree		Don't know	
	n	%	n	%	n	%
Women ¹	21	(27%)	34	(45%)	21	(28%)
Men ²	433	(56%)	227	(29%)	118	(15%)

1 - n = 76 2 - n = 778

The data also revealed a significant association between respondents' sex and sexual orientation and their preference for a relationship with another PLWHA. As can be seen in the Table 19 below, homosexual/bisexual men are significantly more likely than women and heterosexual men to agree with the statement *I prefer to have a relationship with someone who also has HIV*. Over half (56%) of the homosexual/bisexual men agree with the statement, whereas only 44% of heterosexual men and 23% of women agree with this statement. Again the number of lesbians in the sample was too small to allow statistical comparison, but of the eight lesbians who answered this question, three agree, four disagree and one said she doesn't know.

Table 19 Preference for a relationship with another PLWHA

	Agree		Disagree		Don't know	
	n	%	n	%	n	%
Homosexual / bisexual male ¹	406	(56%)	207	(29%)	107	(15%)
Heterosexual male ²	23	(44%)	19	(37%)	10	(19%)
Female ³	15	(23%)	29	(45%)	20	(32%)

1 - n = 720 2 - n = 52 3 - n = 64

6.6 Sexual behaviour with regular partners

6.6.1 Condom use among women who had sexual intercourse with regular partners.

Women in a regular sexual relationship at the time of completing the survey were asked a number of questions about their practice of sexual intercourse (the question was phrased as *vaginal and/or anal intercourse* to include sexual practices of all respondents) in the six months prior to completing the survey. Among the women who had engaged in sexual intercourse, 50% always used condoms, 26% sometimes used condoms, and 24% never used condoms. Of the women who sometimes or always had unprotected sexual intercourse, half (50%) had HIV-positive partners.

Women in sero-nonconcordant relationships were no more or less likely to report that they always used condoms than were women in seroconcordant relationships. However, Table 20 shows that, compared to men in sero-nonconcordant relationships, women in sero-nonconcordant relationships were significantly less likely to report that they always used condoms, and significantly more likely to report that they sometimes or never used condoms.

Table 20 Condom use in regular relationships

Partner serostatus	Frequency of condom use					
	Always		Sometimes		Never	
	n	%	n	%	n	%
Women in seroconcordant relationship ¹	7	(40%)	3	(16%)	7	(44%)
Men in seroconcordant relationship ²	32	(25%)	25	(19%)	71	(56%)
Women in sero-nonconcordant relationship ³	13	(56%)	8	(33%)	2	(11%)
Men in sero-nonconcordant relationship ⁴	103	(71%)	2	(26%)	5	(3%)
1 - n = 17	2 - n = 128		3 - n = 23		4 - n = 145	

6.6.2 Does optimism about new treatments affect condom use in regular relationships?

Analyses were conducted to examine whether women's responses to the question *Do you believe that new combination anti-viral drugs mean better prospects for most people with HIV?* were related to their patterns of condom use during sex with regular partners (see Table 21). Whilst the numbers of sexually active women was too small to allow statistically significant comparisons, it does not appear that greater confidence in new combination anti-viral drugs is related to less safe sexual behaviour in sero-nonconcordant regular relationships of women.

Table 21 Optimism about new treatments and condom use with regular partners of women in sero-nonconcordant relationships

Do new anti-virals mean better prospects for people with HIV?	Frequency of condom use					
	Always		Sometimes		Never	
	n	%	n	%	n	%
Yes	4	(43%)	5	(57%)	0	(0%)
No	9	(64%)	3	(18%)	2	(18%)

n = 23

6.7 Sexual behaviour with casual partners

6.7.1 Condom use among women who had sexual intercourse with casual partners.

Only eight women (10%) reported having sex with a casual partner in the six months prior to completing the survey as compared to 54% of men. Of those women who did have casual sexual partners, four said their casual partners were HIV negative, three said they were both positive and negative or they were not sure and only one woman said her casual sexual partner(s) was HIV positive.

Women were asked a number of questions about their use of condoms during sexual intercourse with casual partners in the six months prior to completing the survey. Among the women who had engaged in sexual intercourse with a casual partner, four said they always used condoms, three sometimes used condoms and one woman did not indicate whether or not she used condoms. One of the three women who said they did not always use condoms reported that all of her casual sexual partners were HIV positive, one woman reported that some of her casual sexual partners are HIV positive and the third woman said that she was unsure of her casual partner(s) serostatus.

I guess there's also the thing about he doesn't like condoms and we never had safe sex once we were diagnosed, we figured well we're both positive and we did the research and at the time it was saying that we had the same virus so we couldn't re-infect each other. So that was fine, we researched it and, you know, made a decision. And since I've gone off the pill I'm terrified of getting pregnant and he doesn't want to use condoms and I've got this thing in the back of my head that I have to be around for Sarah until she can, you know, be self sufficient, 18, 20, or whenever that may be. So that's, that's my goal and I've got this, I imagine, a fear in my head that somehow, you know, they don't know about the virus and somehow even though I've got a higher viral load than him, that he can be... I mean I don't know, I don't know if it's a rational fear or whatever, but giving me more virus. Um...like increasing my level of virus. I mean, who knows, you know, and there's just so many factors about it that you just don't know where to start. So it just spins around in your head out of control.

Debbie, 25, diagnosed 1991

7 Community Life and Community Organisations

Key findings

All of the women have disclosed their HIV status to at least one person. Of the women with dependent children, almost two-thirds have told their children that they are HIV-positive. More than one in ten women said that they have experienced discrimination at some stage. Half of the women reported that they have changed their plans for the future in the last two years. Whilst most of these changes were positive, almost one-quarter were due to declining health.

When seeking advice about treatments for HIV/AIDS women most commonly cited HIV/AIDS media as their main source of information. HIV-positive friends were the most popular for information about living with HIV/AIDS.

Most women have some involvement with HIV/AIDS organisations. More than half are in contact with a Positive Women's group, almost half are in contact with an AIDS council and fewer than a third are in contact with a PLWHA organisation. (These findings are likely to be influenced by the fact that these organisations were a distribution source for the survey). Most commonly, contact with organisations tended to be in the form of newsletters or mailouts as well as treatments advice and social contact. Of the women who do not have any contact a small number said that they either did not know how to join or they fear being identified.

Most women know at least one other HIV-positive person, most commonly acquaintances, friends, past sexual partners or present sexual partners. Similarly most women spend a little or some of their free time with other HIV-positive people. Almost half of the women reported being involved in the care of another person with HIV/AIDS at some stage.

Only a small number of women said they consider themselves part of the gay community, and of this number half identified as lesbian or bisexual. Nevertheless more than two-thirds said they read gay press and more than one-third said they go to gay venues.

7.1 Disclosure

All the women who completed this survey have told at least one person that they are HIV-positive. Most commonly, women have told friends and family that they have HIV/AIDS. Responses to detailed questions about disclosure of HIV serostatus revealed that: 84% have told brothers and/or sisters that they have HIV/AIDS; 80% have told their parents; 79% have told their HIV-positive friends; 88% have told other friends; and 16% have told their

neighbours. Among women who were working at the time of completing the survey, 43% have told their work colleagues that they are HIV-positive.

Among women who have dependent children, 62% have told their children that they are HIV-positive. Women reported telling their children at a range of ages from two years to 25 years. The average age of children at the time of being told of their mother's HIV serostatus was 9 years 4 months.

7.2 Discrimination

7.2.1 *What is the experience of discrimination among women?*

Nine women said that at some stage they have experienced HIV-related discrimination in their local area. Among those who have experienced discrimination, the most commonly cited form of discrimination was verbal abuse, which was experienced by six women. Four women reported that they currently experienced HIV-related discrimination in the area in which they live and, once again, verbal abuse was most common (three out of four). Women were just as likely as men to report that they have ever experienced discrimination, or that they currently experience discrimination due to HIV/AIDS.

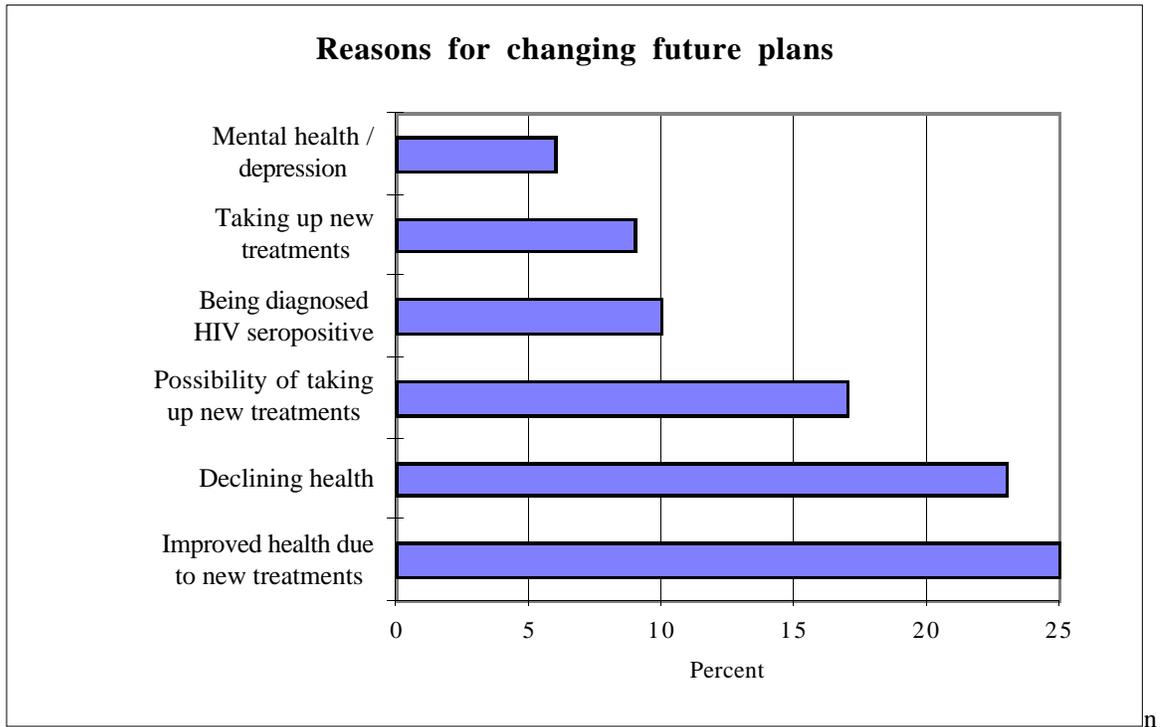
7.3 Planning for the future

7.3.1 *Have women changed their plans for the future? Why?*

Half (49%) of the women who completed the survey reported that in the last two years they have changed their plans for the future. Their reasons for doing so are displayed in Graph 7. While many women said that their plans have changed for apparently positive reasons such as improved health due to new treatments (36%); taking up new treatments (17%); and improved health for other reasons (6%); others gave less positive reasons for a change of plans, such as declining health (23%).

Graph 7

Why future plans have changed in the last two years for women



n = 39

7.3.2 Do women now plan further into the future?

Among women who have changed the time frame they use when planning for major decisions, the most common change was to a longer time frame (see Table 22). There were no differences between men and women in any changes made in the last two years in the time frame used when making major decisions about life.

Table 22 Changes made by women in the last two years in the time frame used when making major decisions about life

Change made	n	%
Use a shorter time frame	16	(20%)
Use the same time frame	41	(52%)
Use a longer time frame	22	(28%)

n = 79

7.4 Information sources

7.4.1 Who do women rely upon for information about living with HIV/AIDS?

Women were asked to indicate which people and/or organisations they rely on for information about living with HIV/AIDS, in particular, whose advice they seek for information about treatments for HIV/AIDS and for information about living with HIV/AIDS (but not about treatments). Women's responses to these two questions are shown in Table 23. The most commonly cited source of information about treatments for HIV/AIDS (80%) was HIV/AIDS media (e.g. *Positive Living*, *Talkabout*). However, HIV-positive friends were most popular for information about living with HIV/AIDS. It is clear from this table that women rely on a variety of people and organisations for information about living with HIV/AIDS, and that in addition to health professionals and PLWHA organisations, friends, partners, and family are important sources of information with regard to living with HIV rather than treating HIV.

Table 23 Sources of information for women

Information source	Source of information about			
	Treatments for HIV/AIDS ¹		Living with HIV/AIDS ²	
	n	%	n	%
HIV/AIDS press	63	(80%)	37	(48%)
Doctor	61	(77%)	36	(47%)
Positive Women's organisation	50	(64%)	41	(52%)
HIV-positive friends	46	(58%)	46	(59%)
AIDS Council/PLWHA organisation staff	33	(42%)	27	(34%)
Alternative therapist	19	(24%)	14	(18%)
Gay press	16	(21%)	9	(11%)
Nurse	17	(21%)	12	(15%)
Friends (not HIV-positive)	11	(15%)	14	(18%)
Family	6	(8%)	7	(9%)
Partner/lover	6	(8%)	15	(19%)
Internet	3	(4%)	-	-
Counsellor/psychologist	-	-	7	(9%)

1 - n = 79 Multiple responses possible

2 - n = 78 Information sources cited by less than 4% of women not shown in table

7.4.2 Are there differences across groups of women in where information is sought?

It is interesting to note that women were significantly less likely than men to report their doctor as their main source of information about treatments for HIV/AIDS (77% vs 92%) and as a source of information about living with HIV/AIDS (47% vs 65%). For the majority of

women, Positive Women's groups provide information about treatments (64%) and living with HIV/AIDS (52%). Lesbian and bisexual women were more likely than heterosexual women to report that they rely on information about living with HIV/AIDS from other HIV-positive friends (88% vs 54%) and that they rely on Gay Press for information about treatments for HIV/AIDS (47% vs 16%). Not surprisingly, men were significantly more likely than women to report that they referred to Gay Press for information about treatments (65% vs 21%) as well as living with HIV/AIDS (53% vs 11%).

7.5 Contact with community organisations

7.5.1 *How many women are in contact with community organisations?*

Most women (86%) report that they have some involvement with HIV/AIDS organisations. More than half (60%) are in contact with Positive Women groups within their state and almost half (45%) of the women are in contact with an AIDS Council in their state. Fewer than a third (28%) said they have contact with a PLWHA organisation. It is probable that this finding is influenced by the fact that these organisations were a vital medium through which the survey was distributed. Because women's organisations are different in each State within Australia a total was calculated for women who had contact with either Positive Women's organisations, AIDS councils and/or PLWHA organisations within each State and is referred to in Table 24 as "Advocacy organisations".

7.5.2 *What type of contact do women have with community organisations?*

Of the women who said they have contact with HIV/AIDS organisations, most women (72%) reported that they receive newsletters or other mail-outs, and 43% receive other services as a client of these organisations. One-fifth of the women (22%) who have contact with an HIV/AIDS organisation work as a volunteer in such an organisation. Among the women who are volunteers in HIV/AIDS-organisations, the number of hours involved in volunteer work ranges from one hour to 20 hours per week, and the average is 6 hours per week.

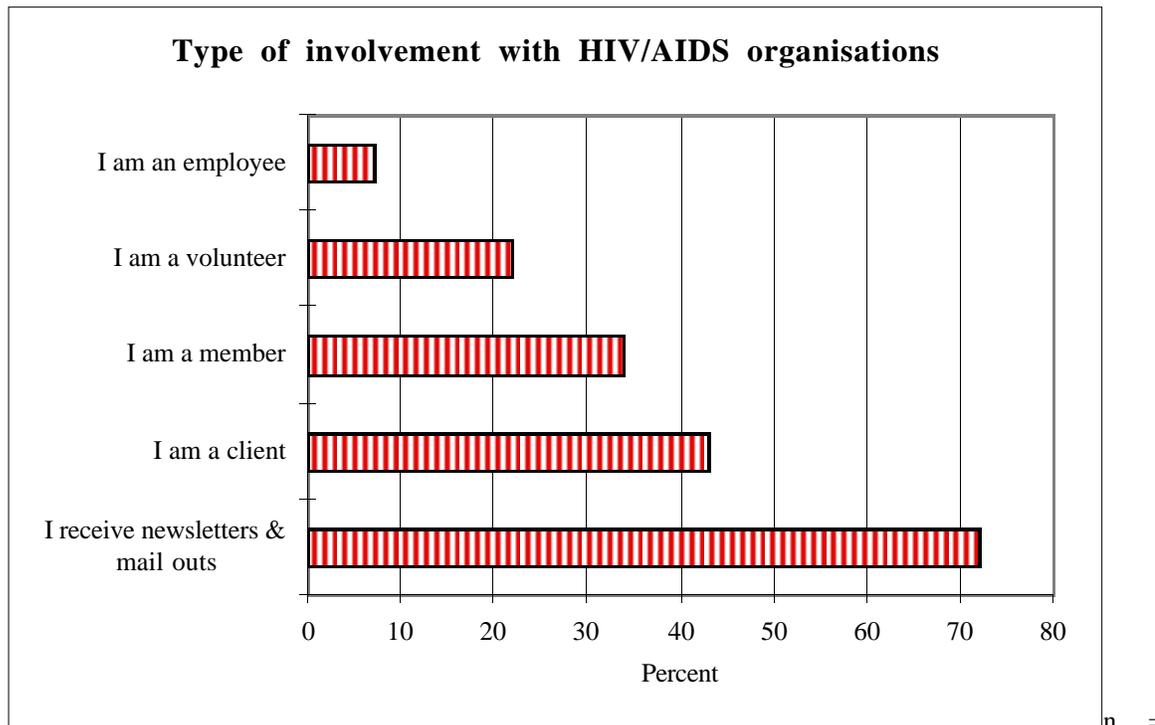
It is interesting to note that women who have dependent children are significantly more likely than women who do not to report that they are a client of an HIV/AIDS organisation (67% vs 35%). Women were significantly more likely than men to report that they receive newsletters and mailouts (83% vs 68%).

Table 24 Organisations with which women have contact

Organisations	n	%
New South Wales-specific organisations ^{††}		
Advocacy organisations	25	(77%)
Positive Women	11	(38%)
CSN	5	(18%)
Positive Heterosexuals (formerly Project Clash)	3	(10%)
Bobby Goldsmith Foundation	1	(4%)
Day Centre	1	(4%)
Ankali	1	(4%)
KWAIDS	1	(4%)
Mark Fitzpatrick Trust	1	(4%)
Victorian-specific organisations ^{††}		
Advocacy organisations	16	(67%)
Positive Women's organisation	16	(67%)
Straight Arrows	1	(4%)
Marriot Trust	1	(4%)
David Williams Fund (VAC)	1	(4%)
Queensland-specific organisations ^{††}		
AIDS Medical Unit	3	(45%)
South Australia-specific organisations ^{††}		
Advocacy organisations	2	(100%)
Positive Women's organisation	2	(100%)
Australian Capital Territory-specific organisations ^{††}		
Advocacy organisations	1	(33%)
Positive Women's organisation	1	(33%)
Western Australia-specific organisations ^{††}		
Advocacy organisations	4	(59%)
Drop-in centre	1	(21%)
Positive Women's organisation	4	(59%)

^{††} - NSW n = 32; VIC n = 23; QLD n = 6; SA n = 2; WA n = 7; ACT n = 3.

Graph 8 Women's involvement with HIV/AIDS organisations



68 Proportion of those in contact with HIV/AIDS organisation

7.5.3 How many women have held decision-making positions with community organisations?

Slightly fewer than one-third (32%) of the women who have contact with HIV/AIDS organisations have ever held a decision-making position in one of these organisations; 13% held a decision-making position at the time of completing the survey.

7.5.4 Which services provided by community organisations do women use?

Table 25 displays the proportion of women who use each of the range of services provided by HIV/AIDS-related organisations. Information and treatments advice were the most commonly used services, but it is clear that the social support provided by HIV/AIDS-related organisations (whether formal or informal) is also used by many women.

Table 25 Use of services provided by HIV/AIDS-related community organisations

Service	n	%
Newsletter / mail-outs	64	(92%)
Treatments advice	42	(60%)
Social contact	31	(45%)
Peer support group	30	(44%)
Counselling	25	(36%)
Informal peer support	25	(36%)
Financial assistance	20	(29%)
Massage	19	(28%)
Library	19	(28%)
Transport services	16	(23%)
Financial Advice	12	(17%)
Domestic help	11	(16%)
Vitamins/meals	3	(4%)

n = 70

7.5.5 Which HIV/AIDS-related publications do women read?

The majority of women (94%) reported that they read HIV/AIDS-related newspapers or magazines *occasionally* or *regularly*. The HIV/AIDS newspapers and magazines read by these women are displayed in Table 26. The data in the table indicate that 68% of women who completed the survey read the national publication *HIV Herald*, 63% read *Positive Living*, 53% read *Talkabout* (PLWHA (NSW)), 53% read *With Complements*, and 38% read *National AIDS Bulletin*. Only four women reported that they never read HIV/AIDS-related newspapers and magazines. These were heterosexual women who do not feel part of the gay community.

Table 26 HIV/AIDS-related newspapers and magazines read by women

Publication	n	%
<i>HIV Herald</i>	52	(68%)
<i>Positive Living</i> (national newspaper)	48	(63%)
<i>Talkabout</i>	40	(53%)
<i>With Complements</i>	40	(53%)
<i>National AIDS Bulletin</i>	29	(38%)
<i>PL</i> (WA magazine)	11	(14%)
Newsletters from community organisations	9	(11%)
Foreign HIV/AIDS press (eg, <i>Poz</i>)	7	(9%)
<i>QPP Alive</i>	1	(1%)
<i>Publications from ASHM</i>	1	(1%)

n = 75 Multiple response possible

7.5.7 Why do some women choose not to be involved with community organisations?

Nine women are not in contact with any HIV/AIDS-related organisations. Three women reported that they do not want to be involved, one said she is not interested, one said she does not know how to join and one said she does not have any contact for fear of being identified. Three women did not indicate why they have no contact.

7.6 Contact with other PLWHA

7.6.1 How many women know others who are living with HIV/AIDS?

Most women know at least one other HIV-positive person. Table 27 shows that most women know friends and/or acquaintances who are also HIV-positive. The four women who reported that they did not know any other PLWHA identify as heterosexual; three live in inner suburbs and one lives in a rural area.

Table 27 Other HIV-positive people known to women

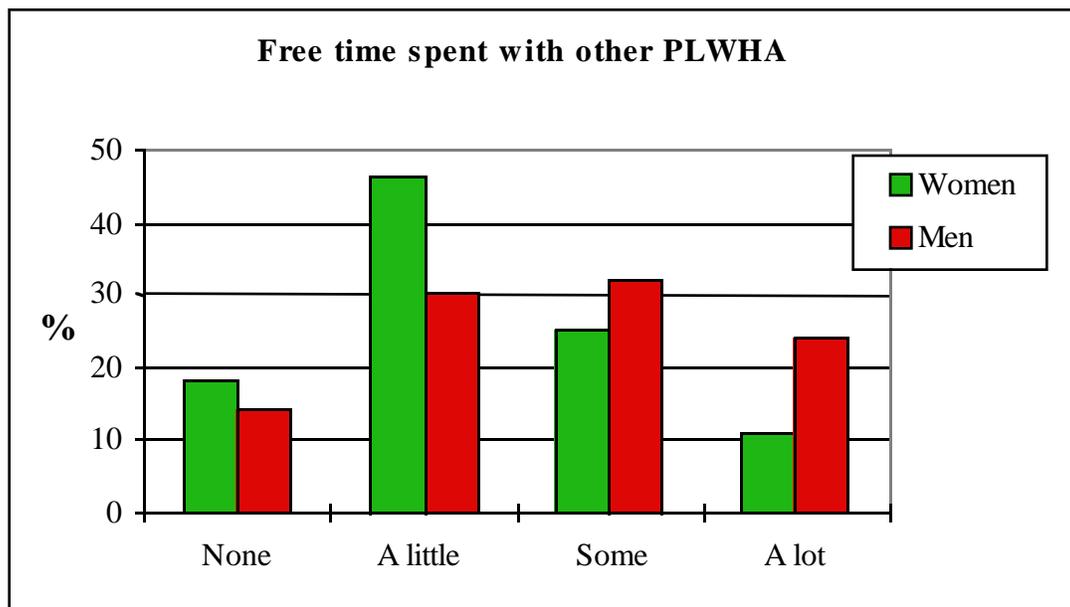
Knows other HIV-positive people	n[†]	%[†]	n	%
No			4	(5%)
Yes			74	(95%)
Friend(s)	51	(66%)		
Acquaintance	58	(74%)		
Past sexual partner	22	(29%)		
Present sexual partner	16	(21%)		
Other family member	4	(6%)		
Child/ren	5	(7%)		

n = 78

† - proportion of women who know at least one other PLWHA

Most women spend at least some free time with other HIV-positive people. Fewer than one-fifth (18%) of the women spend no time with other PLWHA. Men were more likely to spend a lot of time with other PLWHA (see Graph 9).

Graph 9 Free time spent with other PLWHA



n = 868

7.6.3 How many women have provided care for another person with HIV/AIDS?

Slightly fewer than one half (46%) of women have at some time been involved in the care of another person with HIV/AIDS as compared to 56% of men.

7.6.4 How many women have lost someone to HIV/AIDS?

More than half (60%) of the women said that they have lost someone to HIV/AIDS: 53% have had a close friend or relative die as a result of AIDS. Women were significantly more likely to report that they haven't lost anyone to AIDS than were men (40% vs 15%).

7.7 Contact with the gay community

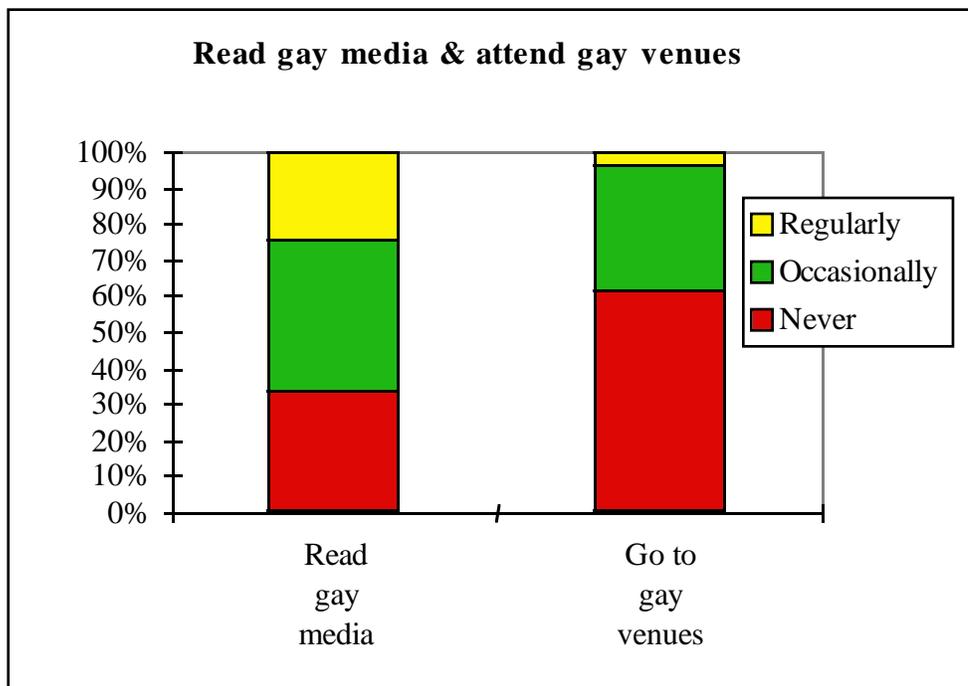
7.7.1 Do women consider themselves part of the gay community?

Only 15% of women said that they consider themselves part of the gay community. Of these women, six women identify as heterosexual, five identify as lesbian and one woman identifies as bisexual. There was a significant difference between women and men who see themselves as part of the gay community (15% vs 72%).

7.7.2 How many women read gay media and attend gay venues?

Whilst only 15% of women said they consider themselves part of the gay community, more than two-thirds of women (67%) said they read gay press and more than one-third of women (38%) said they go to gay venues (see Graph 10). These numbers may be explained by the fact that many women report that they rely on gay newspapers for information about treatment for (21%), and living with (11%) HIV/AIDS. It may also reflect the extent to which an “HIV community” in Australia has been located within the gay community. Women were significantly more likely than men to report that they never read gay press (33% vs 6%) and that they never go to gay venues (62% vs 18%).

Graph 10 Women who read gay media & attend gay venues



n = 78

When I joined Positive Women... I actually made contact with Positive Women, and that was a really important thing to do because I was meeting people who had it for eight years, and nobody lived for eight years with it. And then some woman came and she had only been told that she had it when she'd had it for ten years, and so she was into her 11th year and she was still well. So that was - just being around other people who were surviving was a really good thing. So, I suppose I thought oh yeah, three years or whatever. And I was really uneducated about the whole thing. Like I was this middle class, white, well-educated woman who had access to all the information but I knew nothing about it, absolutely nothing about it.

Belinda, 42, diagnosed 1991

8 Finances

Key findings

One-third of the women who completed the survey reported an income below the poverty line - a similar proportion to that found amongst men. Women were less likely to have an income below the poverty line if they had a partner with whom they share financial resources.

Many women have difficulty meeting their costs of living. The majority of women have difficulty meeting the costs of travel/holidays, restaurants, and entertainment. However, the majority of positive women also have difficulty affording the cost of the basics of life such as utilities (gas, electricity, etc.), housing costs, clothing, and food. Nearly all of the women with dependent children find it difficult to meet the costs of child care. Women with an income below the poverty line have greater difficulty meeting the costs of utilities and transport.

Many women with an income below the poverty line also have few assets. This means that many who currently experience financial difficulty may also experience financial difficulty in the future.

8.1 Income

Table 28 displays the weekly incomes (and equivalent annual incomes) reported by study participants. Twenty-three per cent of women reported incomes below \$11,000. Whilst 37% of women reported incomes of \$35,881 or more, it must be remembered that this question includes partner's income and 38% of women have partners with whom they share financial resources.

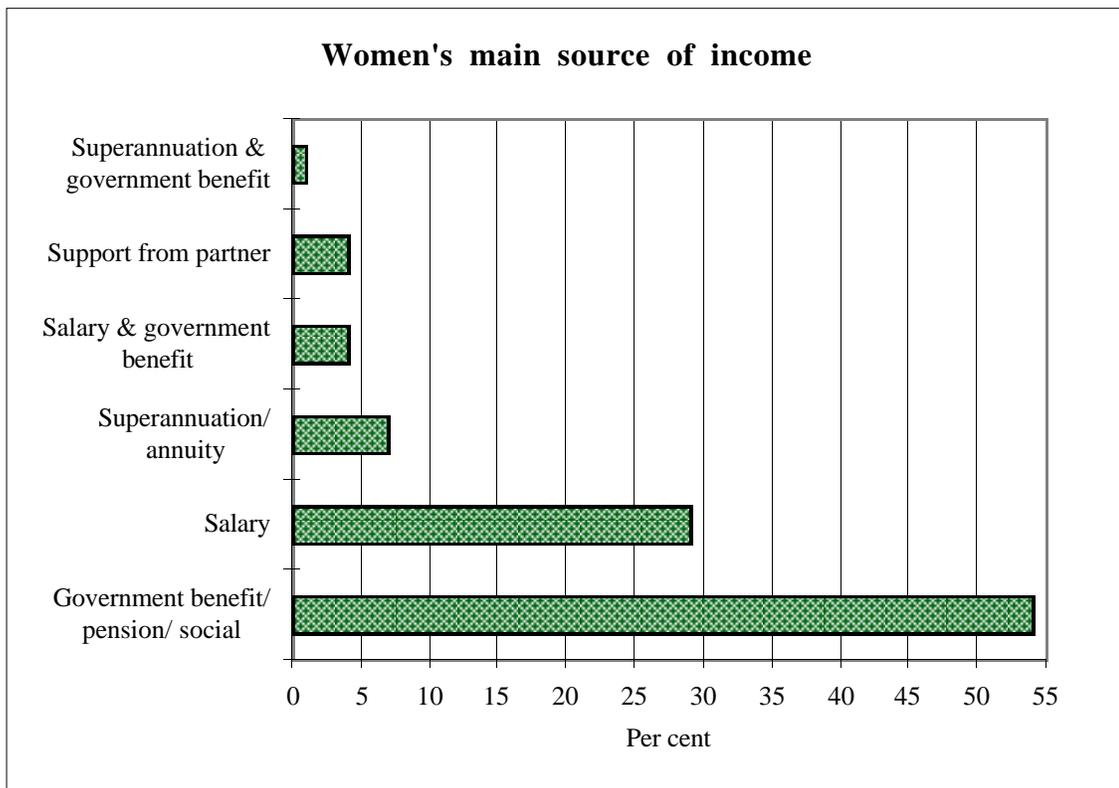
Table 28 Incomes reported by women

Weekly income	Annual income	n	%
\$210 or less	\$10,920 or less	14	(24%)
\$211 - \$330	\$10,921-\$17,160	8	(14%)
\$331 - \$450	\$17,161-\$23,400	6	(11%)
\$451 - \$570	\$23,401-\$29,640	6	(11%)
\$571 - \$690	\$29,641-\$35,880	2	(3%)
\$691 or more	\$35,881 or more	21	(37%)

n = 57

The sources from which women receive their income are displayed in Graph 11. The distribution of incomes reported in Table 28 is probably a reflection of the finding that more than half (54%) of the women who completed the survey reported that their major source of income is a government benefit, pension (commonly a disability support pension), or social security payment, and that 29% reported that their main source of income is a salary. In total, 60% of women reported a government benefit as a source of income, either by itself, or in combination with other income sources.

Graph 11 Main source of income reported by women



n = 77

More than one-third (38%) of women reported that they share financial resources with a partner. Women who are in a relationship were asked their partner's weekly income. The results in the Table 29 indicate that whilst slightly more than one-quarter (27%) of women's partners are earning over \$690 per week, a similar proportion (22%) are earning less than \$210 per week.

Table 29 Income of partner (for women who have a partner with whom they shares financial resources)

Weekly income	Annual income	n	%
\$210 or less	\$10,920 or less	7	(22%)
\$211 - \$330	\$10,921 - \$17,160	2	(8%)
\$331 - \$450	\$17,161 - \$23,400	1	(5%)
\$451 - \$570	\$23,401 - \$29,640	5	(16%)
\$571 - \$690	\$29,641 - \$35,880	7	(21%)
\$691 or more	\$35,881 or more	8	(27%)

n = 30

8.2 Poverty

8.2.1 How difficult is it for women to meet their costs of living?

Respondents were asked a number of questions which assessed the degree of difficulty they have in being able to pay for various expenses. The responses given by women are displayed in Table 30. Of the 12 women who listed child care and related costs as part of their finances in the last six months, 11 said they find it very difficult to meet this cost. General living expenses such as utilities (gas and electricity), rent/mortgage/housing costs and clothing were all listed by more than 70% of women as being a little difficult or very difficult. A surprisingly high proportion of women (54%) have some difficulty meeting the costs of food. The majority of women have some difficulty meeting the costs of travel/holiday (86%) eating/drinking out (81%), entertainment (79%) and complementary therapies (66%). Furthermore, 55% have difficulty meeting the costs of prescribed medicine and transport.

Women were significantly more likely than men to report that it is very difficult for them to meet the costs of medical services (27% vs 10%) and clothing (53% vs 36%). Women were more likely to have difficulty meeting the cost of these items despite the fact that they were no more likely than men to report an income below the poverty line (see section 8.2.2). Women who reported incomes below the poverty line were more likely than other women to report that they have difficulties meeting the costs of utilities (phone, gas, electricity, etc.), and transport.

Table 30 Difficulties experienced by women in meeting various costs of living

Item	a little / very difficult		not at all difficult	
	n	%	n	%
Child care & related costs	11	(92%)	1	(8%)
Travel / holidays	41	(86%)	9	(14%)
Eating / drinking out	54	(81%)	13	(19%)
Entertainment	51	(79%)	14	(21%)
Complementary therapies	30	(76%)	9	(24%)
Utilities	55	(75%)	18	(25%)
Recreational drugs	20	(75%)	3	(15%)
Rent / mortgage / housing costs	42	(73%)	25	(37%)
Clothing	53	(71%)	22	(29%)
Sport / exercise	29	(68%)	14	(32%)
Prescribed medication	32	(55%)	26	(45%)
Transport	41	(55%)	33	(45%)
Food	41	(54%)	35	(46%)
Medical services	27	(46%)	31	(54%)
Support services	14	(34%)	27	(66%)

n = 12 - 76 n varies due to different numbers giving *not applicable* response
 Items cited by less than 2% of women are not shown.

8.2.2 How many women live below the poverty line?

The updated Henderson poverty lines published quarterly by the Institute of Applied Economics and Social Research [IAESR] were used to assess the extent of poverty among PLWHA. Different poverty lines are set for *income units* based on whether the person is single or has a partner with whom they share financial resources, and the number of dependent children. Using the IAESR (1997) data for the June quarter of 1997, it is clear that many women are living in poverty with almost one-third (30%) of women reporting incomes below the poverty line.

It should be noted that because respondents reported their income in bands of sixty dollar width rather than their precise income, it was not possible to calculate exactly the proportion of respondents with incomes below the poverty line - the results reported here are therefore likely to be a conservative estimate.

Table 31 Proportion of women with incomes below the poverty line

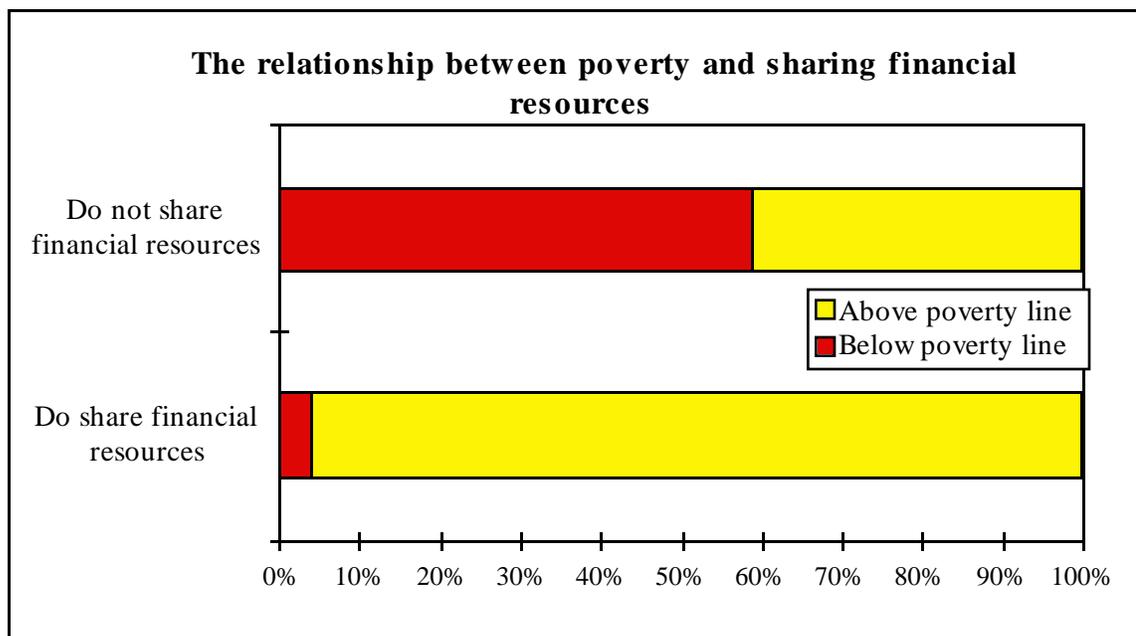
Income unit	income below poverty line		income above poverty line	
	n	%	n	%
Couple	0	0	14	(100%)
Couple plus 1 dependent child	1	(12%)	4	(88%)
Couple plus 2 dependent children	0	(0%)	1	(100%)
Single	3	(36%)	6	(64%)
Single plus 1 dependent child	7	(84%)	1	(16%)
Single plus 3 dependent children	1	(100%)	0	(0%)
Single plus 4 dependent children	0	(0%)	1	(100%)
Total	12 [†]	(30%)	29 [†]	(71%)

n = 40

† - column total does not equal reported total due to rounding in weighting procedure.

Graph 12 shows a striking difference in the prevalence of poverty among women who are in a relationship in which they share financial resources with their partner, and among single women. Women who share financial resources with a partner are significantly less likely to report an income below the poverty line. Similarly, women who have dependent children and are not in relationships are more likely experience poverty than those women who have dependent children but are in relationships (see Table 31).

Graph 12 The difference between women who share financial resources and those who do not



n=57

8.2.3 *What is poverty related to?*

On average, women with incomes below the poverty line reported that they have been HIV-positive for a longer time than women who report incomes above the poverty line (6 years 4 months vs 5 years 3 months). This relationship is likely to be due to the fact that women who are not working have been HIV-positive for a longer period than those who are working (6 years 2 months vs 5 years 6 months). Not surprisingly, a significant association was found between employment status and experience of poverty. Slightly fewer than half (43%) of the women who are not working reported incomes below the poverty line, while only 5% of the women who are working reported incomes below the poverty line.

Reports of income below the poverty line for women were not related to use of anti-viral drugs, use of prophylaxis to prevent PCP or other opportunistic infections. Nor was there was an association between poverty and use of complementary therapies.

8.2.4 *How many women have private health insurance?*

Only 18% of women reported that they have private health insurance. This figure of 18% compares to 44% of all Australian adult women who reported they had some form of private health insurance in the *National Health Survey: Private Health Insurance 1995* conducted by the Australian Bureau of Statistics. Women who reported incomes below the poverty line were no more or less likely than those women who did not to report that they have private health insurance. Similarly women were no more or less likely than men to have private health insurance.

8.2.5 *Do women who live in poverty access different HIV/AIDS organisations?*

Women with incomes below the poverty line are just as likely as other women to have contact with an AIDS Council or PLWHA Organisation. Among women who use the services of HIV/AIDS-related organisations, women with incomes below the poverty line are more likely than other women to use massage and alternative therapies and transport services provided by these organisations.

8.3 *Assets*

8.3.1 *What is the value of women's assets?*

Respondents were asked to estimate the total value of all their assets (including savings, home, car and electrical equipment). The reported value of women's assets ranged from \$0 to \$1,750,000 (mean = \$125,366 and median = \$15,000). More than one-third (34%) of women reported total asset values of less than \$10,000.

8.3.2 *Do poorer women have fewer assets?*

Of those women whose incomes were below the poverty line the average asset value was \$32,616, while those women whose incomes were above the poverty line reported average asset values of \$138,000.

Of the 14 women with incomes below the poverty line, more than one-third (36%) reported assets valued below \$5,000 and 43% reported assets valued below \$10,000. In contrast, among women with incomes above the poverty line, 27% have assets valued below \$5,000 and 32% have assets valued below \$10,000. Overall, of the 51 women who reported their income (and/or their partner's income) and the value of their assets, 12% reported an income below the poverty line and assets less than \$10,000.

I guess I keep, I can keep going on. I feel like I've still got a full life ahead of me, because I've got a job to fulfil. I've got my son, I've got to... I don't think anybody else will be good enough to look after and rear my son. So the way I figure it is I'm, I'm going to kick on to be able to rear him as much as I can, or as long as I can to sort of give him the ideas that, you know, steer him in the right direction - that type of thing.

I've got to bring up my son, and so, I've just got to live on. I've got to put that to the back of my mind and do basically what I'd.... I mean before I knew I was HIV I was still on a pathway, and I still had to go along that pathway. Even though I had HIV, it was like, "Well you can't stop now". You know, you've got to keep going. So I just keep going, and I think, well, you know. Um, until my time's up, I'll just do what I always planned to do. Yep. And maybe in this part of my lifetime, that HIV is going to play a big role in maybe a change in my life, or um, a new career, or, you know, anything. Whatever it is, it's obviously got to, got HIV in it, for me to learn.

Jessica, 32, diagnosed 1996

9 Housing and Accommodation

Key Findings

Half of the women who completed the survey live in rental accommodation, while a third live in a house they own or are purchasing. Many women live with their partner or spouse, and many live with dependent children.

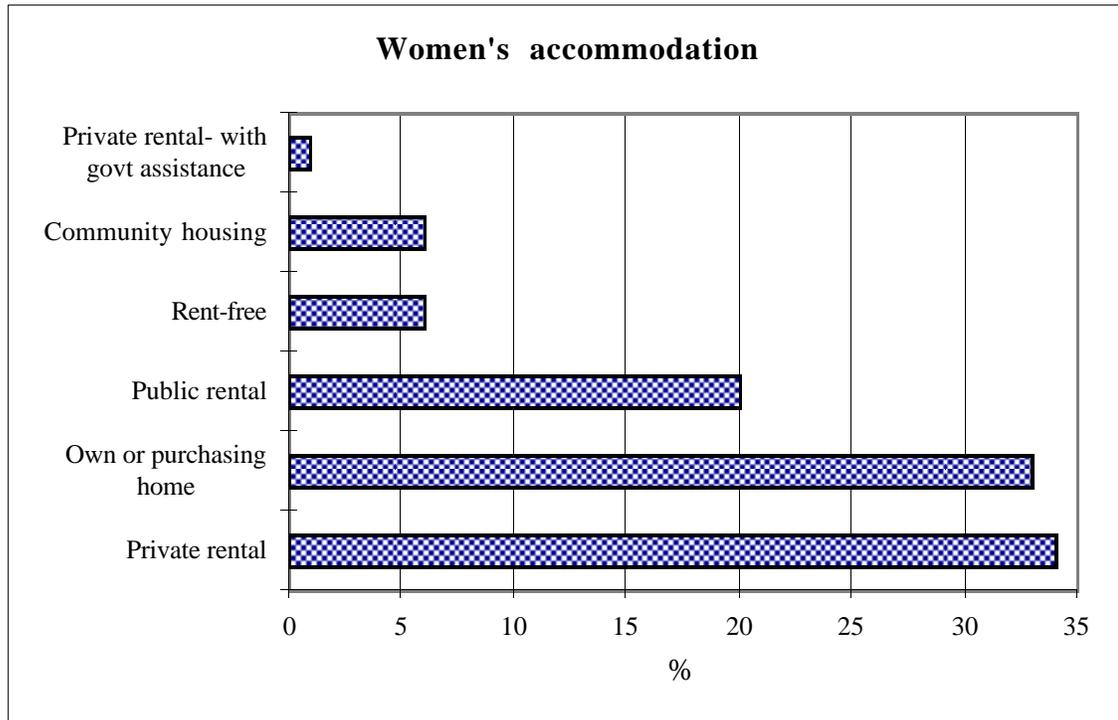
The vast majority of the women believe that their accommodation is suitable for their needs. While women appeared to be satisfied with their current accommodation, nearly half had at some time changed their living arrangements as a result of being HIV seropositive. Most commonly, women had moved closer to support services.

9.1 Housing and accommodation status

9.1.1 *In what type of accommodation do women live?*

Graph 13 reveals that most commonly women are living in rental accommodation with 33% reporting that they live in private rental accommodation, and 20% living in public rental accommodation. Slightly less than one-third (33%) of women live in a home they own or are purchasing, while 33% have owned their own home or flat in the past. Among the women who do not currently own their own home/flat, 24% have owned a home/flat in the past. There were no differences between men and women in terms of home ownership.

Graph 13 Type of Accommodation



n = 78

9.1.2 How much do women spend on accommodation?

Slightly fewer than one-fifth of women (17%) indicated that they pay no rent or mortgage expenses. Women who do have to pay rent/mortgage expenses reported spending between \$21 and \$550 per week on housing. The mean cost of housing for women who were paying either rent or mortgage was \$138 and the median was \$100. There was no difference between men and women in terms of their housing costs.

9.1.3 The people women live with?

Table 32 shows that 27% of the women who completed the survey live alone. Of the remaining 73%, many live with a partner or spouse and/or with dependent children. Not surprisingly, women were significantly more likely than men to report that they live with dependent children (43% vs 3%), whilst men were significantly more likely to report that they either live alone (44% vs 27%) or live with friends or housemates (18% vs 8%).

Table 32 Living Companions of women

Living companions of women	n	%	n	%
Live alone			21	(27%)
Live with others			56	(73%)
Partner / spouse [†]	30	(39%)		
Dependent children [†]	33	(43%)		
Friend(s) / housemate(s) [†]	6	(8%)		
Other family members [†]	6	(8%)		

n = 77 Multiple response possible

9.2 Suitability of accommodation

9.2.1 *Is their current accommodation suitable for women's needs?*

The vast majority (87%) of women believe that their current accommodation meets their needs. The ten women who reported that their accommodation is unsuitable gave a number of reasons why they believe their accommodation is unsuitable. Five women said that their accommodation was in poor condition, three women said it was too small, three women said it was too far from services, two women said it is too expensive for them, two women said their accommodation did not have adequate facilities and two women said they had mobility problems with their current housing arrangement.

9.2.2 *How many women have changed their living arrangements due to HIV/AIDS? Why?*

Almost half (45%) of the women have at some time changed their living arrangements as a result of having HIV/AIDS. The changes women made to their living arrangements the last time they moved are displayed in Table 33. Most commonly women changed their accommodation to move closer to support services.

Table 33 Changes in accommodation due to HIV/AIDS

Most recent change in accommodation	n	%
Moved closer to support services	13	(36%)
Moved to a quieter location	11	(31%)
Better health	9	(25%)
Moved closer to friends	9	(25%)
Stopped working	6	(17%)
Needed cheaper housing	6	(17%)
Planning for illness	6	(17%)
Illness	6	(17%)
Ending of long-term relationship	6	(17%)
Moved out of family home	3	(8%)
Improved finances	2	(6%)
Beginning of new relationship	2	(6%)
Moved in with family	2	(6%)
Moved closer to family	2	(6%)

n = 36 Multiple responses possible Changes cited by less than 2 women not shown

But I think because of HIV and this determination to keep the stress level down, I haven't been very upwardly mobile, you know I think I probably wouldn't have minded pursuing private practice, I might have pursued, um, I would have probably left the public sector, I would have struck out more. I would have thought, well you know hey I've got another, well I was early forties when I was tested, I probably would have thought you know you've got another twenty years of working. But my priority has been, you know, to work and earn a living and have it be interesting, but my health has always been a high priority, so I had to limit, always need to limit my stress levels.

Christine, 50, diagnosed 1989

10 Employment

Key findings

Almost two-thirds of the women who completed the survey are not in paid employment, and most of the women who are working are employed part-time. Two-thirds of the women reported that being diagnosed HIV seropositive affected their career plans. Typically, women had greater difficulty making career plans for the future.

Most of the women who are working have told at least some of their work colleagues that they are HIV seropositive. Amongst women who have not told people at work, many have difficulties keeping their HIV status confidential.

At some stage, half of the women have left work due to HIV/AIDS. Nearly half of these women subsequently returned to work. Most commonly they returned to work for psychosocial reasons (e.g. depression, boredom) or for financial reasons.

Many of the women who were employed at the time of completing the survey are considering changing the type or amount of work they do. Half of the women who were not employed at the time of completing the survey were considering starting work or returning to work. Many women believe that it will be difficult for them to make their desired change in employment status.

Two-thirds of the women using combination anti-viral therapy said that starting this therapy had affected their career plans. These women generally felt better able to plan a work career.

10.1 Employment issues

10.1.1 How many women are employed?

Almost two-thirds (64%) of women who completed the survey are not in paid employment (see Table 34). Among those who are in paid employment, just over half are in full-time employment. Those women who have dependent children were significantly more likely to report that they were not working in paid employment than those women who did not have dependent children (80% vs 49%). Women were no more or less likely than men to be in paid employment at the time of completing the survey.

Table 34 Employment status of women

Employment status	n	%	n	%
Not in paid employment			50	(64%)
Not working / retired	13	(16%)		
Unemployed	12	(15%)		
Student	4	(5%)		
Home duties	22	(27%)		
In paid employment			29	(36%)
Work full-time	13	(17%)		
Work part-time	15	(20%)		

n = 79

Almost two-thirds (62%) of women were in paid employment at the time they were diagnosed HIV-positive. Fifty-seven per cent of the women who were working at the time they were diagnosed HIV-positive were no longer working at the time of completing the survey. Twenty-five per cent of the women who were not working at the time of diagnosis were working at the time of completing the survey.

10.1.2 In what occupations are women employed?

The occupations reported by women are shown in the table below. The high education levels of the sample are reflected in the large proportion of women working in professional occupations.

Table 35 Occupations of women

Occupation	Working¹		Not working²	
	n	%	n	%
Professional	11	(38%)	16	(38%)
Service	8	(28%)	12	(30%)
Clerical and related	4	(14%)	7	(16%)
Production and related	2	(7%)	3	(7%)
Agricultural	2	(7%)	-	
Managerial	1	(3%)	3	(6%)
Sex work	1	(3%)	-	
Sales	-		1	(3%)

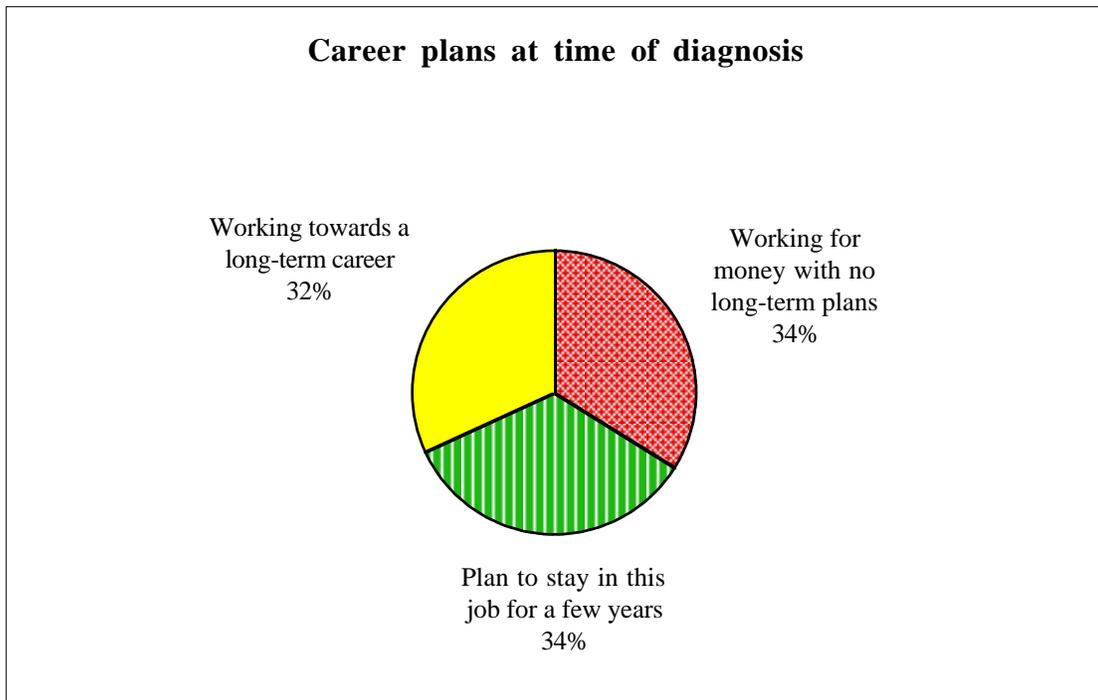
1 - n = 29

2 - n = 41

10.1.3 What were the career plans of women at the time of their HIV diagnosis?

Women who were working when they were diagnosed HIV-positive were asked to describe their long-term career plan at the time of diagnosis. Their responses are displayed in Graph 14, which shows there was an even distribution among women and their career intentions.

Graph 14 Career plans of women who were working at time of diagnosis



n = 49

10.1.4 How did the career plans of women change after their HIV diagnosis?

More than two-thirds (70%) of women reported that being diagnosed HIV-positive affected their work career plans. Women explained a number of ways in which their work career plans had changed. The most commonly cited are shown in Table 36. Many women gave reasons which suggest an inability or unwillingness to plan their career for the future.

Table 36 Effect on career plans of being diagnosed HIV-positive

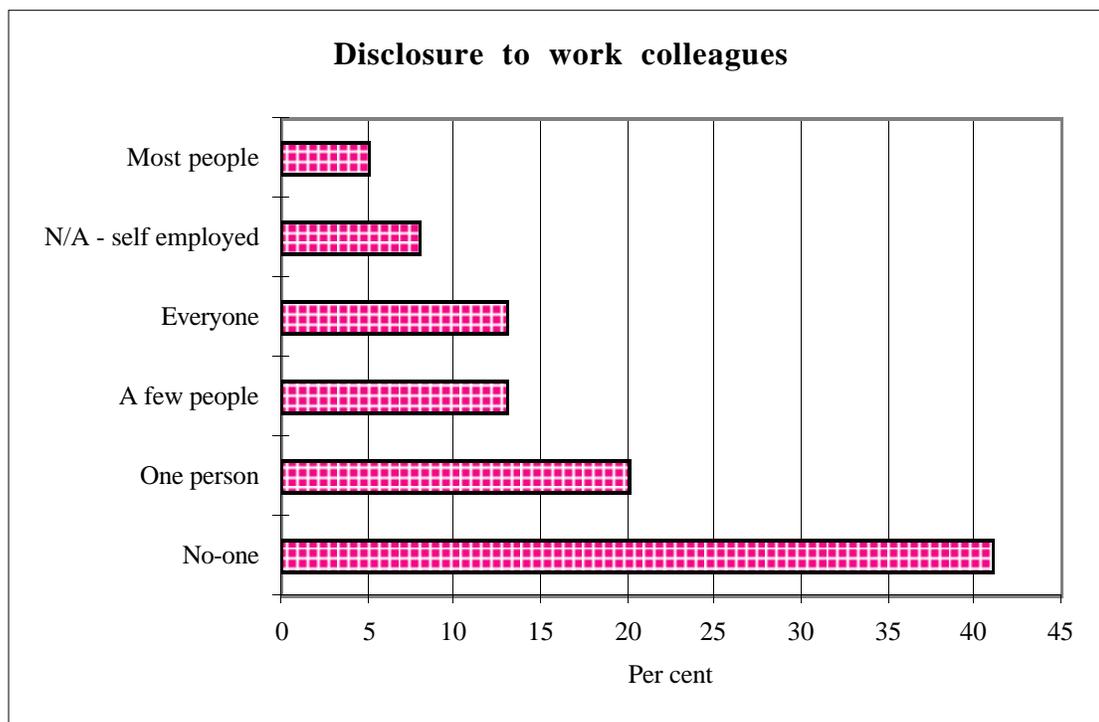
Change in career plans	n	%	n	%
No change to career plans			24	(30%)
Change to career plans			55	(70%)
Career ended / no future career plans	10	(18%)		
Unable to work full-time	7	(13%)		
Uncertain future due to unpredictable health	5	(9%)		
Started new career / changed career	4	(7%)		
Career ended due to ill health	3	(5%)		
Discrimination/gossip	2	(4%)		
Changed to doing something enjoyable	2	(4%)		
Gave up plan to study	2	(4%)		

n = 79 Responses cited by less than two women not shown.

10.1.5 How many women have disclosed their HIV status to colleagues?

The data in Graph 15 show that half (51%) of the women who are working reported that people at their place of work know that they are HIV-positive. However, of that number, most women have disclosed their HIV serostatus to only one or a few work colleagues.

Graph 15 Disclosure of HIV serostatus to work colleagues



n = 29

10.1.6 Do women have difficulties at work keeping their HIV status confidential?

Just over half (55%) of the women reported that they have no problems keeping their HIV status confidential at work. Only one woman reported that she didn't try to keep her HIV status confidential. Table 37 displays the problems encountered by women who reported that they have difficulty keeping their HIV status confidential at work. The most commonly cited problems are difficulty storing and taking medication at work and having to explain absences when attending medical appointments.

Table 37 Problems encountered by women who find it difficult to keep their HIV serostatus confidential at work

Problems keeping HIV status confidential	n	%
Explaining absences from work due to medical appointments	6	(27%)
Difficulty keeping and taking medication	5	(25%)
Visible signs of illness	3	(14%)
Explaining absences from work due to illness	2	(11%)

n = 18 - 22 Multiple responses possible

10.1.7 How many women experience discrimination in the workplace?

Eight of the women who have told people at work of their status reported that they are never given a hard time because of her HIV/AIDS status, one woman said that she is seldom given a hard time, and five women did not indicate whether or not they were ever given a hard time at work.

10.1.8 How easy is it for women to take time off work for health-related reasons?

One woman reported that she never has the flexibility to take time off work when she is sick or requires time for health-related reasons. Five women said they sometimes have this type of flexibility, a further five women said they often have this flexibility, and two women said they always have this flexibility.

10.1.9 How many women have stopped working and why did they do so?

Almost half (48%) of the women reported that at some time they have left work for reasons related to having HIV/AIDS. Of these women, 75% had asymptomatic HIV infection at the time of leaving work, 16% had symptomatic HIV infection, and 9% had been diagnosed with AIDS. The reasons women gave for stopping work are shown in Table 38 - women who had stopped working more than once provided information about the most recent occasion on which they left work. Not surprisingly, women who had experienced HIV/AIDS-related illnesses or an AIDS-defining illness were more likely to report that they left work because of poor health.

Table 38 Reasons given for leaving work due to HIV/AIDS

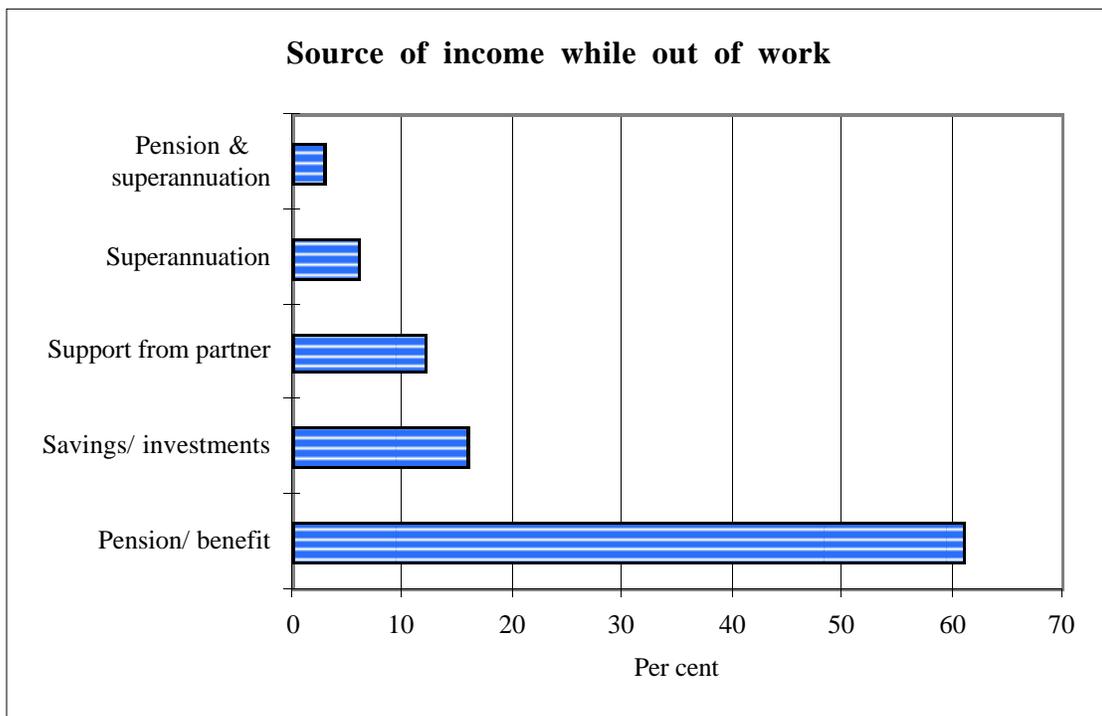
Reason for leaving work	All women	
	n	%
Stress / depression / anxiety	25	(78%)
Low energy levels	17	(53%)
To have more quality time	15	(45%)
Expecting illness in the future	10	(31%)
Poor health	9	(28%)
To move to a different location	7	(22%)
To move to a different job	2	(6%)

n = 32 Reasons cited by less than 2 women not shown in table

10.1.10 What were the sources of income of women while out of work?

Graph 16 displays women’s main source(s) of income during their time out of the workforce. More than half (61%) of the women reported that their main source of income was a government benefit.

Graph 16 Sources of income while out of the workforce



n = 31

10.1.11 How do women spend their time while out of the workforce?

Table 39 shows that women who had left work engaged in a range of activities during their time out of the workforce. Nearly half (47%) of the women spent the time recovering from illness. One-third (34%) of women engaged in volunteer work in an HIV/AIDS-related organisation, and 17% engaged in volunteer work in other organisations. Many women cared for others during their time out of the workforce - 22% cared for another PLWHA and 7% cared for children. Given the large proportion of women who reported low energy levels and/or poor health as reasons for leaving work, it is interesting to observe the substantial number who, upon leaving work, became involved in volunteer work and caring for others.

Table 39 How women spend their time while out of the workforce

How time was spent	n	%
Recreation / sport / leisure activities	15	(47%)
Care of children	14	(44%)
Illness / recuperating from illness	9	(28%)
Care of another PLWHA	8	(25%)
Volunteer work in HIV/AIDS-related organisation	6	(19%)
Studying / self-education	2	(6%)
Looking after self	2	(6%)

n = 32 Reasons cited by less than two women not shown in table
Multiple responses possible

10.1.12 How many women returned to work and why did they do so?

Almost half (42%) of the women who had left work due to HIV/AIDS later returned to work. The reasons given by women for returning to work are shown in Table 40. As can be seen, half of the women who returned to work did so for their mental well-being, self esteem and/or to alleviate boredom.

Table 40 Reasons for returning to work given by women who left work due to HIV/AIDS

Reasons for returning to work	n	%
Mental well-being / self-esteem / boredom	6	(50%)
Money	3	(30%)
Better health / better outlook for the future	1	(8%)
Came to terms with being HIV positive	1	(8%)
Overcame depression	1	(8%)
Social contact	1	(8%)
To be(come) involved in a business	1	(8%)
Need routine	1	(8%)

n = 11 Multiple response possible

10.1.13 How have new anti-viral treatments altered the career plans of women?

Among the women who were taking anti-virals in combination at the time of completing the survey, 26% were working when they started using these treatments. Table 41 shows that two-thirds (68%) of the women who were using anti-virals at the time of completing the survey said that taking up combination anti-virals had affected their career plans.

Table 41 Effect of starting combination anti-virals on career plans

Change to career plans	n	%
There was no change to my career plans	9	(32%)
There was a change to my career plans:		
I began to consider going back to work	5	(18%)
I anticipated a longer time in the workforce	4	(14%)
I began to consider a career plan	4	(14%)
I did not plan to go back to work, and this has not changed	3	(11%)
I left work	3	(11%)

n = 28

Among the women who were not using anti-virals in combination at the time of completing the survey, 48% said that they might use them in the future, 48% were unsure whether or not they would use them in the future and one women (4%) said that she would not use them in the future. Among those who said that they may use combination anti-virals in the future, only four women said that the possibility of using anti-viral drugs has affected their career plans: these women indicated that they are now planning a work career for the first time, are anticipating a longer time in the workforce; or have begun, or are considering, a new career.

10.2 Employment Issues (Among women in paid employment at time of completing survey)

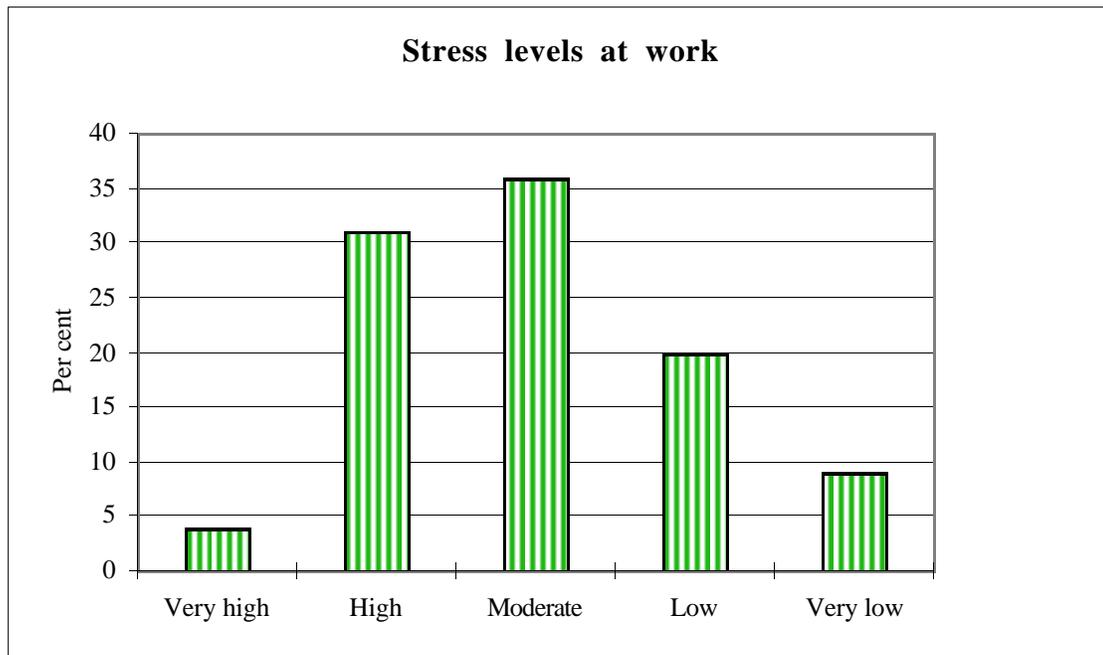
Twenty-nine women were working at the time of completing the survey and provided information about their current work situation. Women who are in paid employment work for an average of 30.1 hours per week (median = 35 hours). They have been in their current job for periods ranging from less than one month to 11 years (mean =3 years 1 month; median = 2 years 4 months).

The majority (79%) of working women reported that their everyday work tasks are not HIV-related. However, six women (21%) reported that their everyday work tasks are HIV-related.

10.2.1 How stressful are the jobs of women who are working?

Fewer than one third of the women who are working reported low levels of work stress. Graph 17 shows that 4% reported very high levels of stress, 31% reported high levels of stress, and 36% reported moderate levels of stress.

Graph 17 Stress levels for women at work



n = 29

10.2.2 How is the work capacity of women affected by HIV/AIDS?

Six of the working women reported that their capacity to perform their work duties is affected by having HIV/AIDS. Three women reported that they cannot always go to work, three women reported that they work reduced hours, one woman reported difficulty concentrating and another said she was affected by tiredness (multiple response possible).

10.2.3 How many women are considering changing their type of work and why?

Seven of the women who are working are considering changing the type of work they do. The main reasons given for wanting to change the type of work are because women want less stress (3), a better paid job (1), a full time job (1), or it is the end of the contract (1). One woman did not say why she was considering changing the type of work she does.

Women were asked how difficult it will be for them to make the desired change to the type of work they do. Two women think it will be somewhat difficult; two women think that it will be somewhat easy; and one woman thinks that it will be very easy. Two women did not indicate how easy they think this will be.

Respondents were also asked to explain the type of (re)training they think they may have to undertake to achieve the desired change in their employment situation. Two women felt they

will require university education, one woman thought on-the-job training will be sufficient and three women reported that they do not believe they will require any (re)training.

10.2.4 How many women are considering changing the amount of work they do? Why?

More than half (57%) of the women who are working are considering changing the amount of work they do. Of the women who want to change the amount of work they do, 56% want to increase the hours worked, 38% want to reduce the hours worked. One woman did not indicate how she would like to change the amount of work she does. Of the six women who said they would like to reduce the amount of work they do, two women reported that they would like to change the amount of work they do because full-time work leaves little time or energy for other activities. The other four reasons given all related to health, including lack of stamina and spending the time to maintain one's health. Of the nine women who said they would like to increase their hours working, two women said they wanted to do this to earn more money. One woman said she would like full-time work to be busier and another woman said she would like to do something worthwhile and different. Five women did not indicate why they would like increased hours of work.

When asked how difficult it will be for them to make the desired change in the amount of work they do, nine women perceived some difficulty: two think that it will be very difficult; seven think that it will be somewhat difficult; three think that it will be somewhat easy; and a further three think that it will be very easy. One woman did not indicate how easy she thinks this would be.

10.3 Employment Issues (Among women who were not in paid employment at time of completing survey)

10.3.1 Do women want to return to work?

Nearly all (96%) of the women who were not in paid employment at the time of completing the survey had been in paid employment at some time in the past. About half (55%) of women who are not working are considering starting work or returning to work.

Of the 26 women who are considering (re)entering the workforce, most think that starting work or returning to work will be difficult: 26% think that it will be very difficult; 44% think that it will be somewhat difficult; 26% think that it will be somewhat easy; and 4% think that it will be very easy.

Approximately half of the women who are considering returning to work think that they will need (re)training through on-the-job training and/or short courses. A substantial minority think that they will need (re)training through courses at a TAFE institute and/or university.

Table 42 Training required to start paid employment or return to paid employment

Training required	n	%
Attending short courses	15	(58%)
On-the-job training	11	(42%)
Education in TAFE	11	(42%)
Education at university	5	(19%)
Training in voluntary organisations	2	(8%)
Computer	1	(4%)
No training	2	(8%)

n = 26 Multiple responses possible

10.3.3 Why do women wish to return to work?

The main reasons women gave for wanting to start or return to work are shown in Table 43. The most commonly cited reasons for (re)entering the workforce are financial considerations, and the second most frequently cited reasons are psychological, emotional, or social - to enhance self-esteem, to relieve boredom, or to enhance mental well-being. The reasons given by women are similar to the reasons for returning to work given by women who returned to work after leaving work due to HIV/AIDS. It is obvious that being out of the workforce will have an impact on the financial situation of women - more than one half (54%) of the women who are not working reported that their main source income is a Government benefit, and women who are working reported significantly higher incomes than women who are not working. Another interesting finding reported in Table 43 is the high proportion of women who want to return to paid employment because of the possibility of working part-time.

Table 43 Reasons given for wanting to (re)enter the workforce

	n	%
Financial reasons	25	(96%)
Psychological / emotional / social reasons	16	(62%)
The possibility of working part-time	10	(38%)
Improved physical health	7	(27%)
Better understanding of the impact of work on health	2	(8%)
Have a child to rear	1	(4%)
The possibility of more flexible work hours	1	(4%)
To help other people	1	(4%)

n = 26 Multiple responses possible

Women who have been in paid employment at some time in the past were asked to describe their last job. Women had been in their last job for periods ranging from one month to 15 years (mean = 3 years 4 months; median = 2 years 6 months), and worked an average of 32.9 hours per week (median = 36.3 hours). These women have been out of paid work for an average of 4 years 4 months (median = 3 years 2 months).

So I guess initially, it was like, OK I'm positive and yeah I'm grieving for myself and I'm thinking about what a terrible future I'm going to have - no future at all - I'll take this scholarship and then I'll die before I have to submit anything and that'll be all right. And then I gradually became a bit more educated about HIV and the fact that I wasn't going to die immediately, so I'd better get on with the rest of my life. And I guess it made me, like I said, it wasn't just HIV that had made me think an awful lot about death and dying and what it meant and what it was in the bigger picture of life. You know, like, you can't have death without life. So, I already had that sort of philosophy I guess. And I saw that, and a lot of the stuff that was going around amongst peer support groups and stuff at the time was that you've got to get on with life, you've got to live it, it's not dying from HIV it's living with HIV. And so, I thought OK I'm just going to make my life as normal as possible.

Belinda, 42, diagnosed 1991

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