Antiretroviral treatments: similarities and differences between women and men

Papers from the HIV Futures I and II surveys and interviews

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ACKNOWLEDGEMENTS

The conference papers and oral poster presentation reproduced here are derived primarily from the HIV Futures I and II Studies. The HIV Futures studies are major research projects conducted over several years, 1997-2000. They have involved a number of researchers in gathering and analysing quantitative and qualitative data. Readers will be aware of the quantitative arm of the studies which has produced a number of major reports since 1998: the two HIV Futures Reports on people living with HIV in Australia, reports on women and HIV in Australia, state-based reports, and reports on heterosexual men and on haemophiliacs and HIV infection.

These quantitative reports are now being accompanied by an increasing number of qualitative reports that include analysis based on both the HIV Futures I and II surveys and a set of associated interviews carried out between 1997 and 2001.

Research projects of this size involve many researchers and many more research respondents. The HIV Futures Surveys were completed in 1997 (n=925) and 1999 (n=924). This research is continuing. The HIV Futures 3 Survey was carried out in Australia in 2001-2002 and at about the same time, the survey was administered for the first time in New Zealand. Reports from these surveys will appear throughout 2002. The Australian HIV Futures 3 Survey will again be accompanied by a set of interviews, which will in turn receive qualitative analysis.

All this research has been made possible through a Collaborating Centre grant from the Department of Health and Ageing.

We gratefully acknowledge the participation of all the survey respondents and interviewees 1997-2001. These respondents constitute a representative sample of all people living with HIV in Australia. The survey is large and demanding to complete. Its representativeness relies totally on the generosity and willingness of respondents and the efforts made by supportive organisations and individuals to reach as many people living with HIV as possible.

We acknowledge the role of many organisations in assisting with the gathering of this data, including state and territory based AIDS councils and PLWHA organisations, the National Association of People Living with HIV/AIDS, the Haemophilia Foundation of Australia and its state affiliates. Each of the major HIV Futures reports carries a full list of participating organisations and individuals.

We particularly acknowledge in this report: Positive Women (Vic), the Women's Projects of: the AIDS Council of New South Wales; the West Australian AIDS Council; the Queensland AIDS Council; Queensland Positive People and the Women's Project at Women's Health Statewide, South Australia.

The HIV Futures Studies each had their own reference group. The Studies are part of the Living with HIV Program, which now has a Living with HIV Reference Group whom we also gratefully acknowledge.

The following researchers worked on the HIV Futures I and II Studies.
HIV Futures: Douglas Ezzy, Richard de Visser, Michael Bartos, Karalyn McDonald, Darryl O'Donnell and Doreen Rosenthal.
HIV Futures II: Jeffrey Grierson, Michael Bartos, Richard de Visser and Karalyn McDonald

INTRODUCTION

'Antiretroviral treatments: similarities and differences between women and men' is a collection of three conference papers delivered between 1998 and 2001. The report provides informed discussion of the differences between women and men living with HIV in Australia with regard to antiretroviral use and their attitudes towards antiretroviral treatment. It is a background briefing document for health service providers, policy makers and people living with HIV and AIDS. The purpose of the report is to support critical reflection on specific aspects of the experience of women and men living with HIV in Australia.

This report complements and extends the discussions found in previous reports published by the Australian Research Centre in Sex, Health and Society, in particular: *Standing on Shifting Sand: Women living with HIV/AIDS in Australia* (McDonald et al, 1998) and *A Complex Uncertainty: Women on health, hope and living with HIV in Australia* (McDonald et al., 2000). It also complements other reports produced by people living with HIV and AIDS such as *Positive Voices. Strengthening the response to HIV and AIDS. Proceedings of the 8th National Conference of People Living with HIV/AIDS, Melbourne, 19-20 April 2001* (NAPWA 2001) and *Positive Work: Women with HIV/AIDS consider a working future* (Positive Women (Victoria) Inc. 1998).

HIV Futures I and II

The HIV Futures Studies I and II were carried out in 1997 (n=925) and 1999 (n=924). They were the largest, most systematic and representative research projects carried out with HIV positive people in Australia. HIV Futures 3 is currently underway. These studies have two components: a major quantitative survey and a set of associated qualitative interviews. Each of the HIV Futures quantitative surveys included representative samples of HIV positive women (see Ezzy et al, *HIV Futures Community Report: Health, Relationships, Community and Employment* and Grierson et al, *HIV Futures II: The Health and Well-Being of People with HIV/AIDS in Australia*).

The HIV Futures Studies are used extensively by health service providers in government, medicine and community sectors. They inform program and policy development, advocacy and cultures of care amongst people living with HIV and AIDS.

The HIV Futures Studies I and II found that the uptake and use of antiretroviral treatments differed significantly between women and men. HIV Futures I found that women (61%) were significantly less likely than men (79%) to be using antiretrovirals. Following the pattern established by the first survey, HIV Futures II also found significant differences in the use of antiretroviral treatments between women (60%) and men (75%). The papers presented in this report also examine the differences between women and men in attitude towards antiretroviral treatments and help to explain these differences.

It is important to note that it is possible that the level of antiretroviral use by women and men reported in the following papers may be higher than in the HIV positive population in Australia as a whole. This is because the survey is more likely to have reached those people living with HIV and AIDS who have some contact with health or welfare/support services than it is to have reached those who are not on treatments and who have less contact with HIV services or groups. For further discussion on questions of sampling see the discussion in Grierson et al*,* 2000: 13-16 and see Law et al*,* 1998.

Whilst treatments uptake rates differ somewhat between the national surveillance data, the HIV Futures surveys and observational studies, it seems likely that about 85% of people living with HIV in Australia have taken highly active antiretroviral therapies (HAART) at some point since 1996. It also seems likely that the uptake of currently available regimes of HAART has peaked and that at any given time approximately 60% of women and 75% of men living with HIV are taking HAART. Almost all those not currently taking HAART at any given time say they are likely to do so should their health status change for the worse. About 50% of all people living with HIV, whether currently on HAART or not, take complementary therapies of various kinds.

The HIV Futures and HIV Futures II surveys indicate various kinds of differences in attitudes to HAART both amongst women and amongst men and between women and men. These attitudes affect both treatments uptake and treatments management strategies. Readers need to be aware that shifts in treatments practices amongst women and amongst men, as well as between women and men, can change over relatively short time periods. It is also quite clear that individuals of both sexes monitor the effects of HAART closely and undertake a range of self-care practices that may vary considerably over time.

We would argue on this basis that there is a need to acknowledge gender differences amongst people living with HIV. It is also important to note that while it is clear that women living with HIV generally distinguish between taking treatments, wider health maintenance practices and the position of HIV in their lives, it is also clear that many men living with HIV also make similar distinctions. However, the reasons these distinctions are made and how they affect ways of living with HIV often differ between women and men.

The experience of side effects from antiretroviral treatment amongst both women and men treating with antiretrovirals appears to have produced a growing distrust of treatments among women. During the second round of interviews conducted in late 2000 and early 2001, it was common for women to comment that most of the clinical trials on treatments appeared to be conducted with men and that no-one was able to provide them with answers that were specific to the female body's response to antiretroviral treatment.

There is an extensive list of research and discussion on these issues up to December 2001, at http://www.thebody.com/treat/women.html. In Australia, McDonald, Bartos and Rosenthal have also discussed these matters in the context of HIV positive women's scepticism about antiretroviral treatment saying:

> concerns have been noted that less is known about the critical question of whether new treatments work differently in women as compared to men, in both efficacy and toxicity, either for biological or exposure-related differences (Watson 1997). In part, this is because fewer women have been enrolled in clinical trials of HIV treatments, sometimes due to the smaller proportion of HIV-infected women in industrialised countries where these trials have taken place, and because of exclusion from trial participation of women of childbearing age (Cotton et al, 1991; Currier et al, 1992; Siegel et al, 1997). It should be noted that this situation has more recently begun to change (Farzedegan et al, 1998; Khalsa et al, 1997)'
>
> (McDonald, Bartos and Rosenthal 2000: 16).

Though these references indicate change is occurring, it is also clear that the exclusion of women in clinical trials is not peculiar to women with HIV (Willis 1997).

Community-based HIV health promotion has also addressed some of these differences through the production of some separate resources such as *Treat Yourself Right: Information for women with HIV and AIDS* (AFAO 2000). However, the relationship between HIV positive women, attitudes to treatments, treatments uptake and the management of side effects is the subject of ongoing discussion in HIV health promotion. Other community-instigated research has identified tensions around gender, sexual identity and treatments education practices in Australia (Hurley 2001a and 2001b):

The three conference papers

'Antiretroviral treatments: similarities and differences between women and men' consists of three conference papers delivered between 1998 and 2001 at national and international HIV and AIDS conferences: the Australasian Society for HIV Medicine (ASHM), annual conference, Newcastle, November 1998; the 13th International AIDS Conference, Durban, South Africa, 2000; and the Australasian Society for HIV Medicine (ASHM), annual conference, Newcastle, October 2001.

Readers will find some repetition of descriptive detail about the HIV Futures I and II Studies across the papers. We have left the descriptions in each paper so that, if they are read or reproduced separately, each still contains sufficient information about the Studies as a whole to maintain the integrity of the research.

The three papers combine quantitative and qualitative research. The HIV Futures I and II quantitative surveys included 84 women in 1997, and 89 women in 1999. In addition, 24 interviews (out of a total of 126 interviews) were conducted with women as part of two interview studies. These interviews took

place with women who lived in Victoria, New South Wales, Queensland and Western Australia. The interviews usually lasted for about an hour and focused mostly on relationships, sexual practice and treatments.

The first paper, ***"****I'm not quickly jumping on 'it's just a chronic illness now bandwagon": Sex differences in relation to HIV antiretroviral treatments* presents data from the first HIV Futures Survey and qualitative project. This paper examines the quantitative data that tells us that women are significantly less likely than men to use antiretroviral treatments and then examines a number of factors such as side effects and difficulties taking medication that contribute to this finding. Data from interviews with women are included in this paper to further explain these differences.

The second paper, *Women and antiretroviral treatment: Gender differences in uptake and attitude* is a poster exhibited in Durban at the 13th World AIDS Conference. The poster combined data from both HIV Futures I and II and was the first presentation where we confirmed the continuing differences between women and men with regard to antiretroviral treatment. Only five minutes was allocated for this presentation so it is necessarily brief. The ideas presented in this paper are expanded in the third paper of this report.

The third and final paper in this report, ***"****There's more to staying healthy than these bloody drugs": gender differences in antiretroviral uptake and attitude'* presents data from the HIV Futures II Survey combined with the interview data from 24 interviews with women and 102 interviews with men. The purpose of this paper was to explain the differences between women and men by way of the interview studies. The interviews provide us with insight into how women and men think about antiretroviral treatments and how treatments fit into their lives.

“I’M NOT QUICKLY JUMPING ON IT’S JUST A CHRONIC ILLNESS NOW’ BANDWAGON”: SEX DIFFERENCES IN RELATION TO HIV ANTIRETROVIRAL TREATMENTS

McDonald K*, Bartos M, de Visser R, Ezzy D, Rosenthal D

Oral presentation based on HIV Futures I Study, Australasian Society for HIV Medicine (ASHM), annual conference, Newcastle, Australia, November 1998.

ABSTRACT

This paper reports on differences between female and male respondents to the HIV Futures Survey, a national, stratified purposive self-administered survey, conducted at the end of 1997. Eighty-four of the 925 PLWHA who completed the Survey were women.

Analyses of the data revealed significant differences between men and women in both practices and beliefs about anti-retroviral treatments. Women were significantly less likely than men to be using anti-retroviral treatments (61% vs 79%) and tended to be less optimistic than men about anti-retroviral treatments meaning better prospects for most PLWHA (37% vs 59%). Women were also significantly less likely than men to be using prophylaxis for opportunistic infections (37% vs 56%), and more likely to be using only complementary therapies.

Multivariate logistic regression analysis of correlates of anti-viral uptake show that for both men and women the most important factor in determining whether or not they are using antiretrovirals is their attitudes toward these drugs. 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. For men, other important factors were disease progression (having been diagnosed with an AIDS-defining illness, and having had a CD4/T-cell count below 400 copies/mL), and seeing their doctor as an important source of information about treatments.

Conclusion: These sex differences indicate that the primary influences on treatments uptake for women were 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.

FINDINGS

The results presented in this paper come from the HIV Futures Survey. The HIV Futures Survey was conducted between July and September 1997 and was completed by 925 PLWHA from all states and territories in Australia. The survey gathered information about the experience of living with HIV/AIDS, including treatments and health management. Of the 925 respondents, 84 were women. Seventy-six men and women who completed the Futures Survey also participated in an in-depth interview. The study was designed to be inclusive of all HIV-positive adults in Australia and particularly targeted women so that a comparison could be made on the basis of gender. In addition to the HIV Futures Community Report published in March 1997, further analysis of data revealed differences between women and men which are detailed in a report entitled *Standing on shifting sand: Women living with HIV/AIDS in Australia* published in August of this year. The title of this presentation is a quote from one of the women who completed an interview.

Arlene, aged 26 and diagnosed in 1990 said:

> 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 effects ... and that kind of stuff that nobody expected that it was coming up 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 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.

The survey revealed that fewer than two-thirds of the women who completed the survey are using antiretroviral drugs. This figure of 58% of women is significantly lower than the figure of 79% of men who reported they are using antiretroviral drugs. Whilst women are significantly less likely to be using antiretroviral drugs than men, it is worth noting that even these figures may be a high estimate due to the fact that the survey was distributed through both PLWHA organisations and medical services and therefore people living with HIV/AIDS who do not have contact with either PLWHA organisations or medical services may be under-represented.

The data also revealed that there are differences in the way men and women view antiretroviral drugs and logistic regression analysis revealed different correlates of antiretroviral use for men and women. For both men and women the most important factor in determining whether or not they are using antiretrovirals is their attitudes toward these drugs. Other important factors for men were markers of disease progression and seeing their doctor as an important source of information about treatments. However, 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. The examination of women’s attitudes exposes an array of concerns about the effects of antiretroviral drugs.

Table 1 Independent predictors of use of antiretroviral drugs

Men
• Confidence in antiretroviral drugs
• Ever had a CD4/T-cell count below 400 copies/mL blood
• Ever had an AIDS-defining illness

Women
• Confidence in antiretroviral drugs
• Use a time frame of “a few months” or “a year ahead”

N = 866

Almost two-thirds of women using antiretroviral drugs reported that they experience side-effects. This table shows that almost half of all women who are using antiretroviral drugs experience nausea, one-third experience fatigue and lethargy, one-quarter experience headaches and one-fifth experience diarrhoea and vomiting.

Table 2 Side effects of antiretroviral drugs

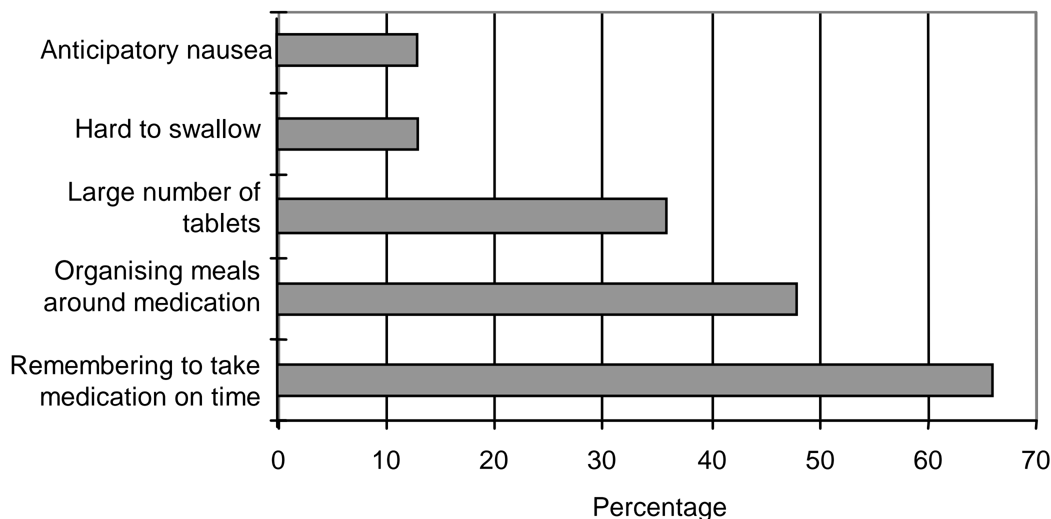
	n	%
	30	63
Nausea		46
Fatigue / lethargy		33
Headaches		24
Diarrhoea		20
Vomiting		20
Skin dryness / rashes / itchiness		15
Metallic taste / tingling / numbness in mouth		13
Dizziness / blurred vision, etc.		13
Weight fluctuation		13

Multiple responses possible
Proportion of those who are using antiretroviral drugs, n = 48

Jane, aged 46, diagnosed in 1993, described how the side-effects of antiretrovirals affected her:

> ...the incentive, I suppose, for somebody to go on to tablets is if they are going to make you feel better, and my experience is that whilst they are physically making me better, and my viral load has dropped and my T-Cell count has gone up, so they are obviously doing my immune system good, um, I don't feel better on them, and that's the difficult thing to weigh up. I'm the one experiencing the discomfort in taking the tablets, I'm the one who's throwing up, I'm the one who's always feeling tired and lethargic and can't walk down the street, can't go to the shop, you know.

Ninety-one percent of women also reported that they experience difficulties in taking their medication. This chart shows that two-thirds (66%) of the women who are using antiretrovirals have difficulties remembering to take their medication on time, and that almost half (48%) have difficulties organising their meals around medications. More than one-third (38%) of the women also reported that they have difficulty taking these drugs in public possibly because they do not want people to know their HIV status. When taken with the finding that 36% of women using antiretrovirals reported that they have difficulties taking large numbers of tablets, the results reported have potentially serious implications for long-term adherence with treatment if less complicated treatment regimens are not found.



n = 49 Proportion of all women using antiretroviral drugs

Figure 1 Difficulties experienced by women taking medication

Janelle, aged 30, diagnosed in 1991, talked about the difficulties she has with her treatment regimen...

> I'm supposed to take three drugs in the morning, one in the afternoon, and three again at night. But I just take three in the morning and three at night, and one extra in the morning and one extra at night. ...after all the tests have been done on men, so women are just given the same, given the same dosage as men. So if I'm going to play around with, well I haven't played around with it too much, but you know, I'm going to fit it into my life. I'm not going to be ruled by it.

One-quarter of the women (26%) who are not using antiretroviral 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 (83%) of women who are not using antiretroviral drugs said that they would consider using these drugs at some time in the future. When women were asked why they would take up antiretroviral treatments, the most commonly cited reasons are related to markers of declining physical health such as a big drop in overall health (80%), a big drop in CD4/T-cell count or big rise in viral load (68% respectively). However, more than half of the women reported that their decision to commence use of antiretroviral drugs is influenced by a belief in the efficacy and/or safety of these treatments (64% respectively).

A series of questions assessed respondents' attitudes toward combination antiretroviral drugs. One-third (33%) of women believe that antiretroviral drugs are harmful, and 32% of women gave a don't know response to this question. Whilst 71% of women actually disagreed that antiretroviral drugs are ineffective, 44% of women said that they don't need combination antiretroviral drugs.

There was also 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 antiretroviral treatments do mean better prospects for most PLWHA (59% vs 37%). A further 51% of women reported that it is too soon to tell if antiretroviral treatments mean better prospects for most PLWHA *(refer 3rd set of bars from top),* 8% said they don't know and 3% of women do not believe that the antiretrovirals mean better prospects.

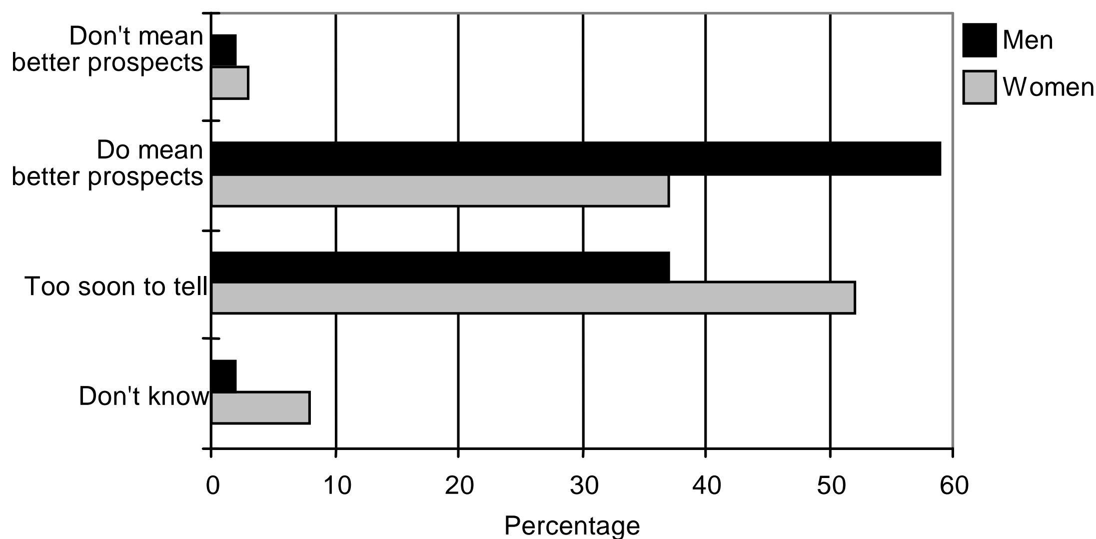


Figure 2 Do antiretrovirals offer better prospects?

Debbie, aged 25, diagnosed in 1991, summarised how she felt about antiretroviral drugs:

> So I guess, on the whole, the drugs really haven't given me any hope about the future. I believe my hope lies in myself...um...to remain positive and find, and to not, not place my hope for my future in these drugs. I refuse to do that because I believe there's a lot more to staying healthy than these bloody drugs.

At the same time, more than two-thirds of women (70%) expressed a belief that new antiretroviral drugs will be developed in time for them to gain benefits. Antiretroviral drugs also allowed some women to plan further into the future.

Patricia, aged 43, diagnosed in 1985 said:

> ...so I was, on the one hand it was like 'How dare you even think that I might be one of the few that may come through this without being affected', but at the same time there was like, still this little thing working in the back thinking 'Oh well, maybe I'm not going to get sick, maybe I'm, you know, not going to die'. But I guess I was too scared to acknowledge that or think it. You see, I think with the treatments it gave me an ability to accept that without tempting fate, I suppose.

Similarly to men, women use various combinations of orthodox medical treatments and complementary therapies. Twenty-one percent of women reported using a combination of antiretroviral drugs and complementary therapies and the same number of women are using complementary therapies only. It is interesting to note that 10% of women reported that they don't use any treatments at all and that women are significantly more likely than men to report that they only use complementary therapies (21% vs 9%).

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 antiretroviral drugs. Women were no more likely than men to be using complementary therapies for HIV/AIDS. However, compared to men, women were significantly less likely to be using prophylaxis for PCP (29% vs 47%), and for other opportunistic infections (22% vs 38%).

Eighty percent of women believe that complementary therapies can improve general well-being and 60% of women believe that use of complementary therapies can delay the onset of HIV-related illnesses. Women also appear to believe that use of complementary therapies in conjunction with orthodox medical treatments can be beneficial: 58% agree that complementary therapies can reduce the side-effects of antiretroviral drugs which is important when considering that more than half (63%) of the women using these drugs reported experiencing side-effects.

The overall impression given by women is that they have mixed feelings about antiretroviral 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 antiretroviral drugs, and that combination antiretroviral drugs are effective, yet women are cautious about their safety and wary of previous negative experiences.

The differences between men and women and antiretroviral uptake indicate that the primary influences on treatments uptake for women are not disease progression, but their attitudes towards treatments and their time frame when planning for the future. The lower uptake of antiretroviral drugs by women living with HIV/AIDS in Australia may be attributable to greater uncertainty about the effects of antiretroviral drugs on women as suggested by both the quantitative and qualitative data. It is important that these differences be recognised by health care workers in order to achieve the best possible health outcome for women living with HIV/AIDS in Australia.

WOMEN AND ANTIRETROVIRAL TREATMENT: GENDER DIFFERENCES IN UPTAKE AND ATTITUDE

Karalyn McDonald, Michael Bartos, Richard de Visser and Jeffrey Grierson

Oral poster presentation based on survey data from the HIV Futures I and II Studies, 13th International AIDS Conference, Durban, South Africa, July 2000.

ABSTRACT

Background: Women living with HIV/AIDS make up only 6% of the total number of people living with HIV/AIDS (PLWHA) in Australia and therefore have often been marginalised in both clinical and social research. Using data from the HIV Futures Survey (1997 & 1999) in Australia, this paper reports on gender differences in attitude and uptake of antiretroviral treatments (ARV) as reported by female and male respondents.

Methodology: The findings presented here are from the HIV Futures Survey (1997) and the HIV Futures II Survey (1999). These surveys were self-administered questionnaires covering a range of demographic, social, attitudinal and health status issues. A large non-clinical sample of men and women living with HIV/AIDS (1997:n=925; 1999:n=924) represents over 8% of the total estimated population of PLWHA in Australia. The survey participants were recruited through HIV/AIDS organisations, medical centres and hospitals, mailing lists of HIV-related publications, and a targeted advertising campaign. In addition to completing the survey, 76 PLWHA, of whom 13 were women, were recruited at random from the survey sample to participate in an in-depth semi-structured interview.

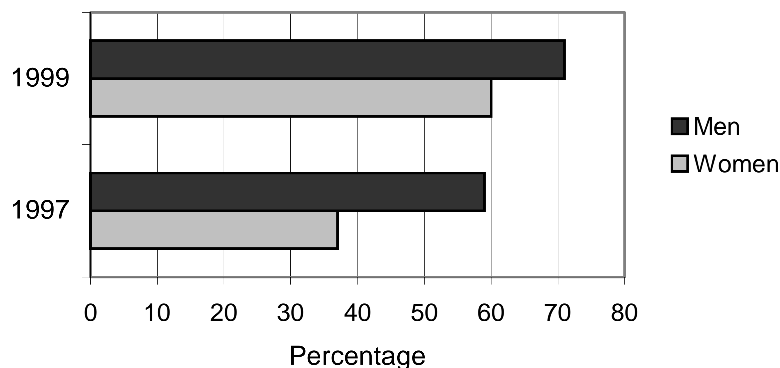
Findings: In 1997 gender differences included women being significantly less likely than men to be using ARV (61% vs 79%, $\chi^2_{(1)}$=17.12, p<.01). In 1999, women were still significantly less likely than men to be using ARV (60% vs 75%, $\chi^2_{(1)}$9.69, p<.01). This difference holds even when health status is taken into account. In 1997 women were also significantly less likely to be using prophylactic treatment for opportunistic infections (37% vs 56%, $\chi^2_{(1)}$=9.71, p<.01). In 1999 there were no longer any significant difference between women and men in relation to prophylaxis (33% vs 33%).

Table 5 ARV use by gender and year

	Women	Men
1997 Using ARV	%	%
Yes	61	79
No	39	21
1999 Using ARV		
Yes	60	75
No	40	25

1997 N=859, 1999 N=913

In both 1997 and 1999 women were significantly less optimistic than men about ARV meaning better prospects for most PLWHA (1997: 37% vs 59%, $\chi^2_{(1)}$=13.36, $p<.01$; 1999: 60% vs 71%, $\chi^2_{(2)}$ =8.38, $p<.05$).



1997 N=877, 1999 N=905

Figure 3 Agreement with the statement "ARV mean better prospects for most PLWHA"

Interview data shows that men generally had positive feelings about antiretroviral therapies. While their experience of using these therapies had been accompanied by significant negative side effects, they nevertheless felt that combination ARV had created a more positive future both for them and for PLWHA generally. Women, in contrast, were very sceptical about the efficacy of antiretroviral therapy. In particular, women tended to be unwilling to pin their hopes for the future on ARV.

The majority of men interviewed expressed cautious optimism about their future options and tied their optimism to their current success on treatments:

> I suppose I'm cautiously optimistic about the future with combination therapy. We're certainly in a better position now than we were 10 years ago, that's for sure. And so hopefully in another 10 years we'll be in an even better position. So, while I still have concerns about - as I mentioned before, about combo therapy and how long it is going to work for people, what's going to happen when they run out of combinations if we do? There are issues that are going to cause great concern. On the whole I'd have to say that we're in a better position than we were.
>
> [Tim, aged 40, diagnosed 1988]

In contrast, women were far more cautious than men about the effectiveness of antiretroviral treatments. In particular, women tended to resist placing much reliance on treatments in their sense of future:

> So I guess, on the whole, the drugs really haven't given me any hope about the future. I believe my hope lies in myself...um...to remain positive and find, and to not, not place my hope for my future in these drugs. I refuse to do that because I believe there's a lot more to staying healthy than these bloody drugs.
>
> [Debbie, aged 25, diagnosed 1991]

Discussion

Both male and female PLWHA have expressed attitudes of cautiousness towards antiretroviral treatment despite the rapid uptake of ARV. Whilst women have been slower to take up these therapies, the difference in attitude between the sexes has reduced, as combination antiretroviral treatment has become the standard of care for PLWHA in Australia. Understanding gender differences in uptake and attitude to ARV is a crucial component to providing effective and appropriate health care to both men and women living with HIV/AIDS in Australia.

"THERE'S MORE TO STAYING HEALTHY THAN THESE BLOODY DRUGS": GENDER DIFFERENCES IN ANTIRETROVIRAL UPTAKE AND ATTITUDE.

Karalyn McDonald and Jeffrey Grierson

Oral presentation based on HIV Futures I and II Studies, Australasian Society for HIV Medicine (ASHM), annual conference, Melbourne, Australia, November 2001.

ABSTRACT

Background: Women living with HIV/AIDS in Australia make up only 6% of the total number of people living with HIV/AIDS (PLWHA) and therefore have often been marginalised in both clinical and social research. Using data from the 'HIV Futures Survey' (1997 & 1999) in Australia, this paper reports on gender differences in attitude and uptake of antiretroviral treatments (ARV) as reported by female and male respondents.

Method: The 'HIV Futures Survey' was a self-administered questionnaire covering a range of demographic, social, attitudinal and health status issues. This large non-clinical sample of men and women living with HIV/AIDS (n=921) represents over 8% of the total estimated population of PLWHA in Australia. An associated long interview study (n=76) conducted interviews in 1998 with participants from the 'HIV Futures Survey'.

Results: In 1997, gender differences included women being significantly less likely than men to be: using ARV (61% vs 79%); using prophylactic treatment to treat opportunistic infections (37% vs 56%); and less optimistic than men about ARV meaning better prospects for most PLWHA (37% vs 59%). In 1999, women were still significantly less likely than men to be using ARV (60% vs 75%). This difference holds even when health status is taken into account. In 1999 there was no longer any significant difference between women and men in relation to prophylactic treatment (33% vs 33%). In addition, women were significantly less optimistic than men about ARV meaning better prospects for most PLWHA (60% vs 71%), although the difference between men's and women's optimism is much less pronounced than in 1997. Interview data shows that men's views about ARV were embedded in the gay community response to HIV/AIDS while women felt isolated from both community and medical responses to HIV. Quantitative and qualitative data also showed women with dependent children were more likely than other women to take up ARV.

Conclusion: Both male and female PLWHA have expressed attitudes of cautiousness towards antiretroviral treatment despite the rapid uptake of ARV. Whilst women have shown to be slower on this uptake, the difference in attitude between the sexes has reduced, as combination antiretroviral treatment has become the standard of care for PLWHA in Australia. Understanding gender differences

in uptake and attitude to ARV is a crucial component to providing effective and appropriate health care to both men and women living with HIV/AIDS in Australia.

FINDINGS

This paper reports on results from the Australian HIV Futures Studies. Part of these studies includes a survey that was first conducted at the end of 1997 and again at the end of 1999. It is a national, anonymous mail-back questionnaire covering a range of demographic, social, attitudinal and health status issues.

There were 925 valid responses to the 1997 survey and 924 responses to the 1999 survey representing over 8% of the total estimated population of PLWHA in Australia on each occasion. The survey includes PLWHA from all Australian regions; from inner urban, suburban and rural areas; men and women; gay and straight.

In addition to completing the survey, 126 interviews were conducted with PLWHA; 102 with men and 24 with women. Interviewees were recruited from the survey samples to participate in in-depth semi-structured interviews.

Results

For those people who are not familiar with the HIV Futures I and II Studies I would like to present a few results from the survey data analysis to set the background for the analysis that we undertook with the interview data.

Firstly, the survey data shows that women were significantly less likely than men to be using antiretrovirals. This was the case in both 1997 and 1999. In 1997 only 61% of women compared with 79% of men were using ARV ($\chi^2_{(1)}$17.12, p<.01) and in 1999 only 60% of women compared with 75% of men were using ARV ($\chi^2_{(1)}$9.69, p<.01). This difference holds even when health status is taken into account.

Optimism about ARV meaning better prospects for most PLWHA was also significantly different between women and men. In 1999 60% of women compared with 71% of men felt that ARV meant better prospects and in 1997 the percentages were 37% of women agreeing compared with 59% of men. (1997: 37% vs 59%, $\chi^2_{(1)}$=13.36, p<.01; 1999: 60% vs 71%, $\chi^2_{(2)}$ =8.38, p<.05).

At this point I would like to show you the results of the qualitative data. It is important to note that the gender differences focused on in this paper are mainly between women and gay men. The numbers of

bisexuals, heterosexual men and lesbians who participated in the qualitative study are too small to allow generalisations.

The interview data shows that men generally had positive feelings about antiretroviral therapies. While their experience of using these therapies had been accompanied by significant negative side effects, they nevertheless felt that combination ARV had created a more positive future both for them and for PLWHA generally. Women, in contrast, were very sceptical about the efficacy of antiretroviral therapy. In particular, women tended to be unwilling to pin their hopes for the future on ARV.

The majority of men interviewed expressed cautious optimism about their future options and tied their optimism to their current success on treatments:

> I suppose I'm cautiously optimistic about the future with combination therapy. We're certainly in a better position now than we were 10 years ago, that's for sure. And so hopefully in another 10 years we'll be in an even better position. So, while I still have concerns about - about combo therapy and how long it is going to work for people, what's going to happen when they run out of combinations if we do? … On the whole I'd have to say that we're in a better position than we were.
>
> [Tim, aged 40, diagnosed 1988]

In contrast, women were far more cautious than men about the effectiveness of antiretroviral treatments. In particular, women tended to resist placing much reliance on treatments in their sense of future:

> So I guess, on the whole, the drugs really haven't given me any hope about the future. I believe my hope lies in myself ... to remain positive, and to not place my hope for my future in these drugs. I refuse to do that because I believe there's a lot more to staying healthy than these bloody drugs.
>
> [Debbie, aged 25, diagnosed 1991]

Discussion

The gender differences in antiretroviral uptake and attitude as revealed by the HIV Futures Studies can be explained by the discourses women and men use to describe their experiences and attitudes towards ARV. The discourse used by gay men tends to be embedded in the historical and cultural context of gay community. Even men who are not necessarily long-term survivors but who have been diagnosed in the last five years, that is since the availability of ARV in Australia, still often refer to differences between now and then – a before and after treatments as part of their discourse.

The men in our studies tend to express their experience with a much broader frame of reference. Treatment expectations tended to be based on both individual and collective histories of engagement with the AIDS epidemic.

Simon when asked about his reaction to his diagnosis said,

> Because I'd been involved with it and been around with it for so long and had so many friends go and stuff so I think you tend to become a little bit fatalistic. So it doesn't come as any surprise when they say 'You do have it' … and probably in your deep subconscious you're preparing yourself for it anyway.
>
> [Simon, aged 49, diagnosed 1997]

Whereas women only talk about a before and after treatments if they were diagnosed before the availability of ARV and even then, usually only if they are advocates or activists of other women living with HIV.

> … it's still a thing that frustrates me now when I meet newly diagnosed women who are put on treatments immediately. They haven't had a chance to even learn to live with HIV let alone to learn about treatments and to learn what's best for them. So I think – That's part of women not having much of a community. They don't get to share that information with each other before they go on it.
>
> [Janelle, aged 32, diagnosed 1991].

Women's discourse is more likely to be based on their own experience and even then they often situate this experience within their family life. This is often recounted as the impact that treatments have on other family members whether this be the hope that family members invest in ARV, the impact that the side-effects may have on family life or the potential for longevity; particularly so when the woman has a dependent child or children.

Many women interviewed also talked about their need to minimalise the impact that HIV has on their life. The women who were taking the drugs spoke of wanting "a normal life". These women saw taking ARV as necessary to get on with the other things in life that they had always intended to do.

> I'm not going to dwell on the fact that I'm sick and I've got AIDS. It's like that's not important any more. Okay, it was when I got it, but the kids are more important. Me being here for the kids is like – medications, the virus, you don't think about it. And because I don't talk about it, it's not a thing to them either. … I just come across as a normal person like them.
>
> [Catherine, aged 31. diagnosed 1990].

For other women, taking ARV was a constant reminder of the impact HIV had had on their life and therefore, if they believed their health did not warrant it, they were not on ARV.

> I think that for me treatments did reinforce my positive status, but so I mean that's probably around why the compliance was a bit difficult for me as well. So since I'm not on treatment I feel like that's not being reinforced every day as it was.
>
> [Janelle, aged 32, diagnosed 1991]

Whereas most of the gay men in our study were more accepting of taking treatments, and tended to see it as a function of health maintenance. Richard summed this up:

> [The treatments are] working very well for me, except, I've been through the protease inhibitors, I've been through the AZT in the eighties all that kind of stuff, even though my T-cell count's weren't bad. It was really just a matter of saying I want to take everything I can to make sure I stay alive.
>
> [Richard, aged 52, diagnosed 1984]

CONCLUSION

Both women and men in our studies expressed attitudes of cautiousness towards antiretroviral treatment despite the rapid uptake of ARV. Whilst women have been more reluctant to take up these therapies, the difference in attitude between men and women has reduced as combination antiretroviral treatment has become the standard of care for PLWHA in Australia.

The interview studies shed further light on these differences of gender in uptake and attitudes towards ARV. For most men, the experience of ARV is situated both socially and historically. Whereas for women, their experience of ARV is a more personalised and individualistic experience. In general, women haven't experienced HIV collectively.

Assumptions that ARV will occupy the same positions in the lives of men and women many not be appropriate. It is important to consider gender as part of the treatment equation so that effective as well as appropriate health care is provided to both men and women living with HIV/AIDS in Australia.

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