

Motherhood and HIV positive women in Australia

Papers from the HIV Futures I & II surveys and interviews

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CONTENTS

Acknowledgements	1
Introduction	2
Michael Hurley and Karalyn McDonald	
1. The role of motherhood in relation to antiretroviral treatment	7
Karalyn McDonald and Michael Bartos	
Oral presentation based on HIV Futures I, Australasian Society for HIV Medicine (ASHM), annual conference, Perth, Australia, November 1999.	
2. Treatments, health and pregnancy among women living with HIV/AIDS in Australia	15
Karalyn McDonald	
Oral presentation based on survey data from the HIV Futures I and II, Australian Women's Health Conference, Adelaide, Australia, February 2001.	
3. 'I always wanted to have children': motherhood and HIV-positive women in Australia	23
Karalyn McDonald	
Oral presentation based on HIV Futures I and II, International Congress on AIDS in Asia and the Pacific (ICAAP) Conference, Melbourne, Australia, October 2001.	
References	31

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The conference papers and posters reproduced here are derived primarily from the HIV Futures I and II Studies. These studies are major research projects conducted over several years (1997-2000) and 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 haemophiliacs and HIV infection.

These quantitative reports are now accompanied by an increasing number of qualitative reports that include analyses 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, which are carried out over a number of years, 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. At about the same time, the HIV Futures NZ 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.

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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

Motherhood and HIV positive women in Australia collects together as a report three conference papers delivered between 1999 and 2001. This report is aimed at health service providers, policy makers and people living with HIV and AIDS. It details empirical information and informed discussion about the ways motherhood is understood amongst HIV positive women in Australia, and how this affects their lives. It is a background briefing document that supports critical reflection on specific aspects of the experience of women living with HIV in Australia.

The 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* (1998) and *A Complex Uncertainty: Women on health, hope and living with HIV in Australia* (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 I and II studies were carried out in 1997-98 and 1999-2000. They are the largest, most systematic and representative research projects carried out with HIV positive people in Australia. HIV Futures 3 is currently underway. Both studies had two components: a major quantitative survey (1997, n=925; 1999, n=924) and a set of associated qualitative interviews. Both the Futures quantitative surveys included representative samples of HIV positive women.

The HIV Futures Reports 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.

Of the 13,963 people living with HIV and AIDS in Australia in 1999, 914 were women (NCHECR 1999). By 2001 this number had risen to 990. An increase in the number of women infected is not, however, indicative of increased rates of HIV infection amongst women. Between 1999 and 2001 the number of women infected as a proportion of all HIV infections had risen only slightly from 6.5% to 6.7% (NCHECR 2001). For further information on the epidemiology of HIV infection amongst women in Australia see the national HIV database (NCHECR 2001).

The HIV Futures Studies I and II confirmed that the experiences of HIV positive women were not always the same as those of HIV positive men (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*). As the following papers reveal, the women who participated in the HIV Futures Studies are a diverse group at different stages of life. Some

have grown up children, others live with dependent children and some have no children. For two thirds of the women, parenthood was seen as important to their sense of identity. Though most of the women surveyed in Futures II are not considering pregnancy in the future, motherhood remains a central focus of their lives.

About half of the female respondents to HIV Futures II (n=89) had dependent children. There were sixty children dependent on these women. Twenty-two women had a total of thirty-four children born to them since they were diagnosed with HIV. Others had non-dependent children.

The three conference papers

This report consists of three conference papers delivered between 1999 and 2001 at national and international HIV and AIDS conferences: the Australasian Society for HIV Medicine (ASHM) annual conference, Perth, December 1999; the Australian Women's Health Conference (AWHC), Adelaide, February 2000, and; the International Congress on AIDS in Asia and the Pacific (ICAAP) October 2001.

Readers will find some repetition of descriptive detail about the HIV Futures Studies I and II across the papers. We have left the descriptions in each paper so that they can be read independently of each other and 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 live 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. In the ensuing conversations about relationships, it soon became apparent that women's lives often revolved around their families, which for many included children.

Women have also differed significantly from men in their uptake and use of antiretroviral treatments. 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%). See the separate report *Antiretroviral treatments: similarities and differences between women and men* on antiretroviral treatment and similarities and differences between women and men.

The first paper, *The role of motherhood in relation to antiretroviral treatment*, arose from the finding in the 1997 HIV Futures Survey that women with dependent children were significantly more likely

to be using antiretroviral treatment than women without dependent children. The authors then explored the qualitative data from interviews with 13 women to examine what lay behind this finding.

It is important to note that this significant difference amongst HIV positive women in 1997 was not repeated in the 1999 HIV Futures Survey. That survey confirmed quite rapid shifts in perceptions of treatments amongst HIV positive women. Women with dependent children were now no more likely to use antiretroviral treatments than women without dependent children. 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. Further, 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 inclusion of women in clinical trials generally 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 relation 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 and other community instigated research has identified tensions around gender, sexual identity and treatments education practices in Australia (Hurley 2001a and 2001b).

The second paper, *Treatments, health and pregnancy among women living with HIV/AIDS in Australia*, combines both survey and interview data in a summary of the more important findings

from the report, *A Complex Uncertainty: Women on health, hope and living with HIV in Australia*. The audience was not necessarily familiar with either HIV or the HIV Futures Studies so it was pertinent to explain the studies, the methodologies and some of the demographic findings from the surveys.

The third and final paper in this report, *'I always wanted to have children': Motherhood and HIV-positive women in Australia* presents data from the HIV Futures II Survey combined with the interview data from 24 interviews with women. The focus of this paper was the importance of the role of motherhood in the lives of women living with HIV in Australia. This paper examines four of the themes that emerged from the interviews including: having a job to do; protection and autonomy; disclosure to children; and the possibility of motherhood for women who were not yet mothers.

THE ROLE OF MOTHERHOOD IN RELATION TO ANTIRETROVIRAL TREATMENT

Oral presentation based on HIV Futures I, Australasian Society for HIV Medicine (ASHM), annual conference, Perth, Australia, December 1999.

Karalyn McDonald and Michael Bartos.

Abstract

This paper reports on how women living with HIV/AIDS conceptualise the use (or non-use) of antiretroviral treatments in relation to their role as mothers. The data presented here are from the HIV Futures Survey, a national, stratified purposive self-administered survey, conducted at the end of 1997. Eighty-four of the 925 people living with HIV/AIDS (PLWHA) who completed the survey were women. Of these women, 48% had between one and four dependent children.

The survey results reveal that women with dependent children were significantly more likely to be using antiretroviral treatment than were women without dependent children (76% versus 46%). Women with dependent children also held more positive attitudes to antiretroviral treatment on a number of measures. However, women with dependent children did not differ from those without on health status measures.

Thirteen women from the Eastern states of Australia were also interviewed as part of a larger HIV Futures qualitative study and of these five had dependent children, three had adult children and one woman had a child who had died of AIDS. The interview data suggest women with dependent children are more optimistic about the success of antiretroviral treatment because their caution is modified by their optimism about fulfilling their role as mothers.

The differences between women with dependent children and those without indicate that women with dependent children are more confident and optimistic about antiretroviral treatments. While women with children are cautious about antiretroviral treatment their role or duty as mothers tips the balance of caution in favour of antiretroviral use.

Introduction

The results presented in this paper come from the HIV Futures I 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 from the Eastern states of Australia who completed the Futures Survey also participated in an in-depth interview.

In previous papers from the HIV Futures Survey, the data have revealed that women are less confident than men about antiretroviral treatment and less optimistic about antiretroviral treatments providing better future prospects for PLWHA. (see McDonald, K., et al, *Antiretroviral treatments: similarities and differences between women and men*). The aim of this paper is to explore the differences between women with dependent children and women without dependent children in attitude and uptake of antiretroviral treatment.

This paper will also highlight the apparent contradictions revealed in the HIV Futures Survey data and I will refer to the interview data collected from the 13 female participants who participated in the Futures interview study to suggest reasons for these contradictions.

Results

To begin I want to give you some background information about the 84 women who completed the Futures Survey in 1997. Almost half (48%, n=38) reported having dependent children, and of these women, 22 (58%) said they had one dependent child, 11 (29%) said they had two dependent children, three women (8%) said they had three dependent children and one woman said she had four dependent children. See Figure 1.

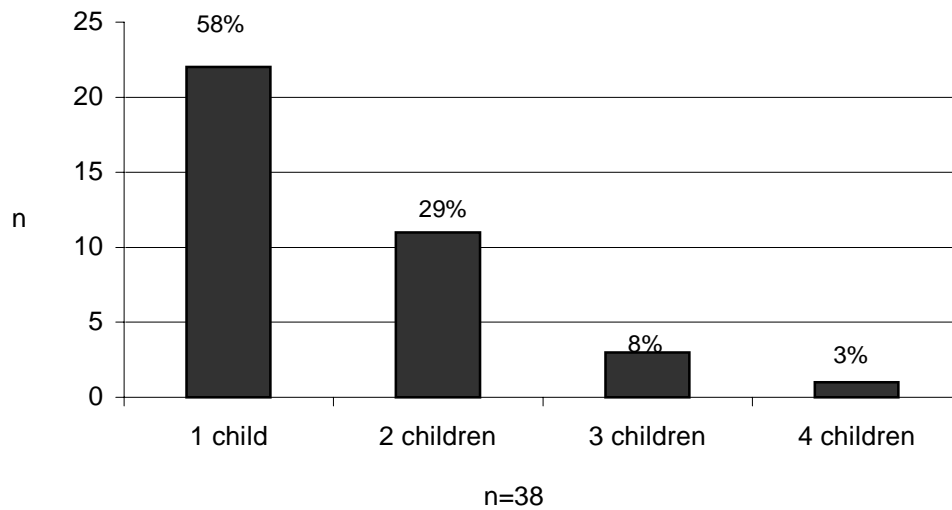


Figure 1: Women with dependent children

Twenty-eight women said they had disclosed their HIV status to their children. The children’s age at time of disclosure ranged from two years to 25 years: the average age was 11 years.

Of the 13 women who also participated in an in-depth interview, six had dependent children, three had adult children and one woman had a child who had died of AIDS. Of the nine women interviewed who had children, six were using antiretroviral treatments to treat their HIV-infection. One woman with children not using antiretroviral treatments had been on treatment but suffered severe side-effects and was due to start a new combination the week after the interview.

Most notably the survey results revealed that women with dependent children were significantly more likely to be using antiretroviral treatment than were women without dependent children (76% versus 46%, $\chi^2_{(1)}=7.43$, $p<.01$). See Figure 2.

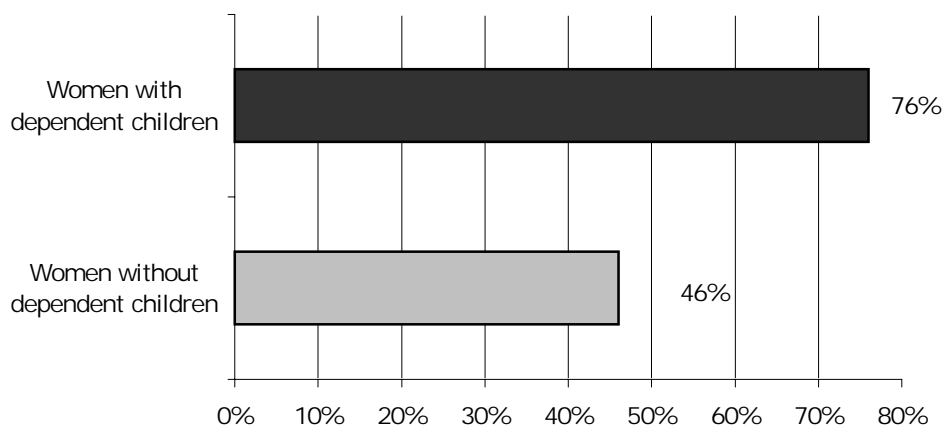


Figure 2: Women using antiretroviral treatment

Women with dependent children also held more positive attitudes to antiretroviral treatment on a number of measures. Respondents were asked to indicate whether they agreed or disagreed with a number of statements about antiretroviral treatment for HIV infection. Women with dependent children were significantly more likely than women without dependent children to agree with the following statements:

'Combination antiretroviral drugs have allowed me to plan my life with confidence for the long-term' (64% versus 36%) ($\chi^2_{(2)}=6.83, p<.05$)

'People with HIV should start using antiretroviral drugs as soon as possible' (71% versus 29%) ($\chi^2_{(2)}=7.18, p<.05$)

'Combination antiretroviral drugs have made my life better' (65% versus 34%) ($\chi^2_{(2)}=8.36, p<.05$). See Graph 3.

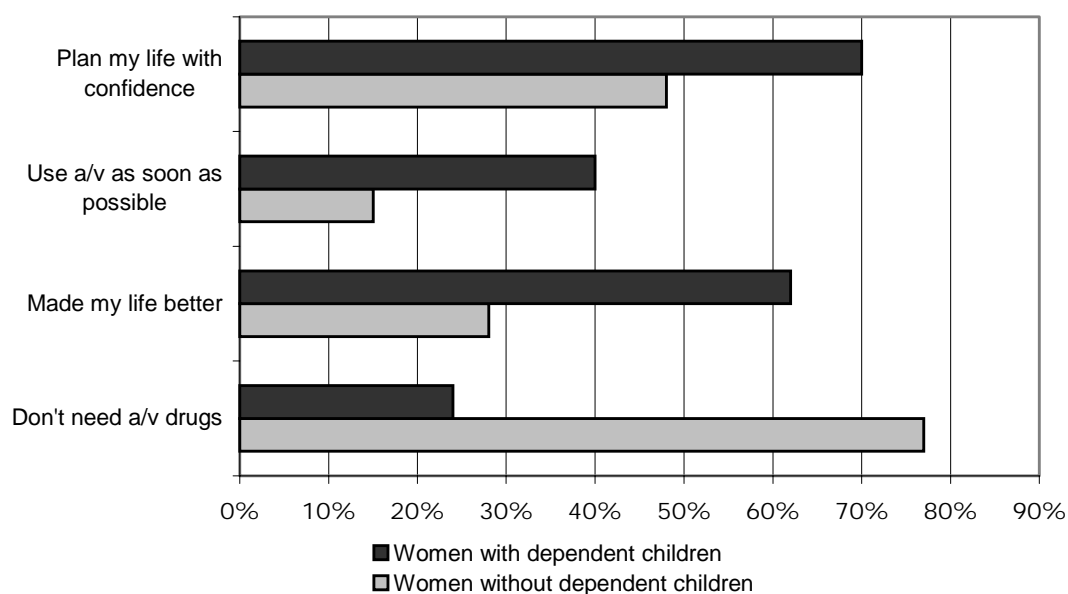


Figure 3: Differences between women with and without dependent children

Women with dependent children were significantly more likely than women without dependent children to disagree with the statement:

'I am healthy now and do not need to use combination antiretroviral drugs' (77% versus 24%) ($\chi^2_{(2)}=13.96, p<.01$)

However, women with dependent children did not differ from those without on measures of health status or health behaviours. Women with dependent children were no more likely than women without dependent children to:

Have had an AIDS-defining illness (8% versus 8%)

To rate their health as poor or fair (31% versus 24%)

Be using alternative/complementary therapies (61% versus 55%)

Have difficulties taking medication in public (42% versus 58%)

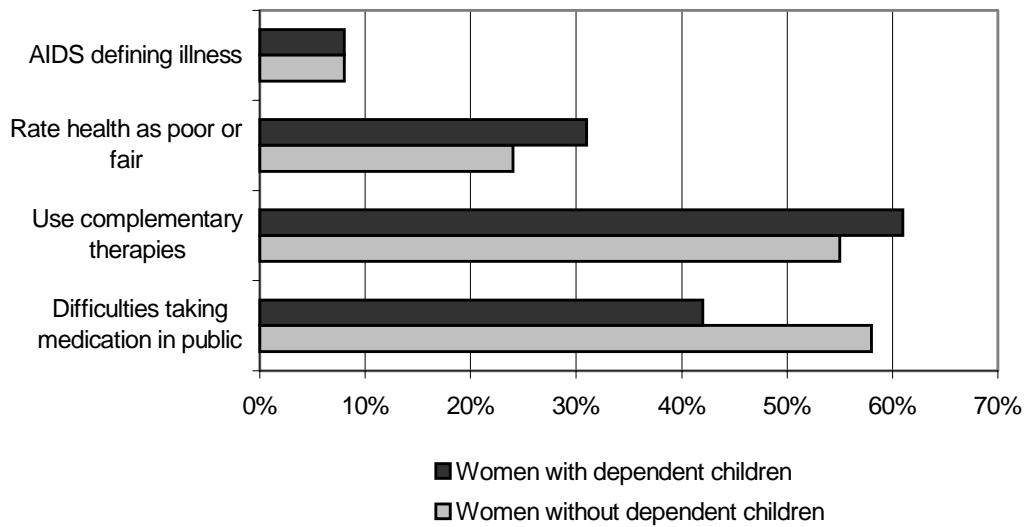


Figure 4: No difference between women with and without dependent children

Women with dependent children were also no more likely than women without dependent children to:

- Have had a bad experience with antiretroviral treatment (37% vs 54%)
- Disagree that combination antiretrovirals are ineffective (50% vs 50%)
- Disagree that combination antiretrovirals are harmful (54% vs 46%)

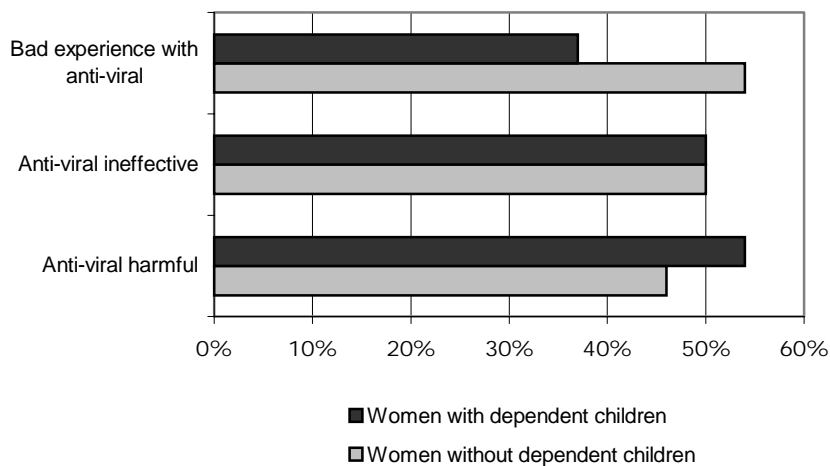


Figure 5: No difference between women with and without dependent children

So, the question I want to address is why women with dependent children are the same as other women when it comes to rating the efficacy and safety of antiretrovirals, but are much more likely

than other women to say antiretrovirals should be used as soon as possible and that antiretrovirals have made their lives better and enabled them to plan for the future.

The answer to this question lies in the qualitative data we have collected where positive women talk about antiretrovirals in relation to their roles and obligations as mothers:

Jessica, aged 32, diagnosed 1996, child aged 4 years:

'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'.

Similarly, Melissa, aged 28, diagnosed 1995, three children aged 2, 5 and 9 years:

'I want to be here for my kids to grow up. And I am determined that I will be'.

The obligations of motherhood also help explain the apparent contradiction between denying antiretrovirals create a better future and asserting they will prolong life.

Debbie, aged 25, diagnosed 1991, child aged 3 1/2 years:

'We never took the drugs to have a sense of hope about our future. ... I guess I've taken the medication to hopefully suppress the virus enough so there's less damage now, so that I can hopefully have a longer life with my child. I mean she's my total motivation for taking the medication'.

So, despite the obvious caution, women clearly relied on antiretroviral treatment to extend their longevity:

Patricia, aged 43, diagnosed 1985, 2 children aged 16 and 12 years:

'So a couple of years ago I sort of thought OK it's ten years, I'm ten years into this, statistically this is when I get sick, you know, and die. And I thought well, I mean, even if I do start getting sick now, if my T Cells start dropping now and I start treatments, I've still got, like what, four years or five years or maybe even seven years of the treatment juggle. So that's, [my daughter] - she was fourteen then, so she'd be 20. And it's like, at least she's old enough to look after herself you know'.

Sarah, aged 36, diagnosed 1994, child aged 2 years talked about her doctor managing her treatments:

'And because the longer it, they work and the better drugs they get, well there's more chance you've got all the time that my system hasn't been severely damaged. So all they've got to do is maintain me ... I mean, I suppose for me since we've got Andy is that, you know, I said to [my doctor], when I saw her, I said now I've got Andy you keep telling me ten years, well that was three years ago and things are looking a lot better now, I'm holding you to it'.

Also interesting is the **lack** of significant difference between women with dependent children and women without dependent children from the survey data in the belief that antiretroviral treatments have improved prospects for people living with HIV/AIDS (45% versus 29%). This is possibly

explained by the confidence or hope that women place in antiretrovirals for their own future but they are reticent to extend this hope to other PLWHA.

Of the three women in the interview study without children, only one was taking antiretrovirals. The other two women were very cautious about treatments and preferred to wait for further treatment outcomes before they committed themselves to the regimen of combination therapy:

Arlene, aged 26, diagnosed 1990, no children:

'...even though it may prolong my life, still may not, I mean it's really unknown, 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 um, I guess seeing all that kind of stuff has made me think twice about it'.

Conclusion

The quantitative Futures data illustrates the differences between women with dependent children and those without. Women with dependent children are more confident and optimistic about antiretroviral treatments with regards to making their lives better and enabling them to plan for the future, but cautious about the efficacy and safety of antiretrovirals, and no more likely to agree that antiretrovirals mean better future prospects for most PLWHA.

The interview data sheds light on these apparent contradictions and suggests that while women with children are cautious about antiretroviral treatment their caution is modified by their optimism about fulfilling their role as mothers. This role or duty as mother tips the balance of caution in favour of antiretroviral use.

The differences between women with dependent children and those without highlighted in this paper are important factors in understanding the experiences of women living with HIV/AIDS in Australia. Motherhood is both a central component of positive women's narratives about living with HIV and often a determining factor in decisions about antiretroviral use.

TREATMENTS, HEALTH AND PREGNANCY AMONG WOMEN LIVING WITH HIV/AIDS IN AUSTRALIA

Oral presentation based on survey data from the HIV Futures I and II, Australian Women's Health Conference, Adelaide, Australia, February 2001.

Karalyn McDonald.

Abstract

Women living with HIV/AIDS make up approximately 6% of all people living with HIV/AIDS in Australia (NCHECR, 1999). The impact of living with the virus differs in some fundamental ways for women and men because of social, environmental and personal issues.

This paper reports on the experiences of women living with HIV/AIDS in Australia and in particular, issues of treatments, health and reproduction. The data presented here are from the HIV Futures I and II Surveys, national self-administered surveys conducted in 1997 and in 1999. Over 900 people living with HIV/AIDS (PLWHA), including over 80 women, participated in each of the surveys. In addition, 23 women participated in interview studies that further explored the complexities of life as an HIV positive woman. This paper will bring together these data sets and discuss the health issues pertinent to women living with HIV/AIDS in Australia.

Introduction

The HIV epidemic in Australia has been dominated by men. To a greater extent than in almost any other country, the epidemic, which began among gay men, has largely remained confined to that population. As well, relatively early stabilisation of the rate of HIV incidence has meant that the size of the epidemic in Australia has remained small by global standards. In this epidemiological context, women with HIV in Australia find themselves on the margins of the global epidemic among women, and on the margins of the largely male epidemic in Australia. However, the reality is that 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 paper discusses the experiences of women living with HIV in Australia in relation to treatments, health and children. Where pertinent, I will highlight the differing experiences of women and men living with HIV.

Method

This paper reports on results from the Australian HIV Futures Surveys I and II. The HIV Futures Study is the first large-scale survey of the social, medical and economic aspects of living with HIV/AIDS in Australia. It is a national, anonymous, self administered, mail-back questionnaire. The first HIV Futures Survey was conducted at the end of 1997. It was then repeated again at the end of 1999 and will be carried out for the third time at the end of this year. On each occasion, a purposive sample of people living with HIV/AIDS in Australia was recruited through HIV/AIDS organisations, mailing lists of HIV-related publications, various health and social service agencies, such as hospitals, doctors' surgeries, as well as a targeted advertising campaign.

The survey gathered demographic information as well as behavioural and attitudinal aspects of a number of domains relating to the social impacts of living with HIV/AIDS which include: health status and health maintenance; antiretroviral treatments, prophylaxis and complementary therapies; social and economic life including employment and accommodation, as well as relationships and sexual practice. In 1999, mental health and recreational drug use were included in the survey.

There were 925 valid responses to the 1997 survey and 924 valid responses to the 1999 survey representing over 8% of the total estimated population of people living with HIV/AIDS in Australia on each occasion (NCHECR, 1997 & 1999). The survey includes people living with HIV/AIDS from all Australian regions; from inner urban, suburban and rural areas; men and women; gay and straight. The majority of respondents are gay men, reflecting the epidemiology of HIV in Australia, but particular recruitment efforts were made to ensure representation in the sample of numerically smaller groups such as HIV-positive women so that a comparison could be made on the basis of gender, as well as those infected through injecting and through blood products.

This paper focuses on the women who participated in the HIV Futures Studies. In 1997, of the 925 respondents, 84 were women, and in 1999, of the 924 respondents 89 were women. This represents 9% and 10% of Australian HIV-infected women in Australia respectively, as estimated by the *Australian HIV Surveillance Report* (NCHECR, 1997 & 1999).

In order to maximise the reach of the survey, large numbers of questionnaires were distributed and unused questionnaires were not returned, so it is not possible to calculate response rates.

In addition to the surveys, qualitative studies exploring the attitudes of people living with HIV/AIDS towards antiretroviral treatments, and the use or non-use of antiretroviral drugs for HIV/AIDS in relation to any changes or impacts on personal relationships and work-related issues. Following the 1997 Futures Survey, 76 people living with HIV/AIDS, of whom 13 were women, participated in an in-depth semi-structured interview. After the 1999 HIV Futures Survey, 50 people living with HIV/AIDS, of whom 10 were women, participated in an in-depth semi-structured interview.

The sample for the interviews was drawn from survey respondents who indicated their willingness to participate in an interview. Interviews were conducted in four sites across the Eastern seaboard of Australia and Western Australia, representing inner urban, suburban, and regional locations. Personally identifying data was removed from the transcripts and pseudonyms have been used throughout this paper to protect the confidentiality of the participants.

In this paper I will mainly present results from the 1999 survey, but where results are particularly important I will make comparisons with the 1997 results. Only results achieving significance below p-values of .05 are reported.

Results

I would like to start the presentation of the results with some demographics of the women who participated in HIV Futures II. Three quarters of the women who participated in this survey are Australian born and a further five percent identified themselves as Aboriginal/Torres Strait Islander. The women who participated came from all states and territories with the majority from New South Wales and Victoria. Most women identified as heterosexual (83%), and this was reflected in self-reported transmission with 67% of women reporting that they were infected via heterosexual contact. Eleven percent of women identified as lesbian and six percent as bisexual.

Women's ages ranged from 18 to 62, with an average of 38 years. High levels of education were evident, with twenty-five percent of women holding a University degree, twenty-three percent a tertiary diploma, and a further twenty percent completing secondary education. More than half of the women (52%) had been positive for between five and ten years, eighteen percent for more than ten years and twenty percent for less than five years.

Health

As most readers will be aware, there are currently two tests that many HIV-positive people undertake to monitor the progression of the virus. The viral load test measures the viral replication whilst the CD4/T-cell test measures the immune system. Our data shows that the women surveyed regularly monitored their own health with 98% of women reporting having had a viral load test and 99% of women having a CD4/T-cell test.

We also asked participants to rate their own health on a four-point scale ranging from excellent to very poor. The majority of women (71%) rated their health as 'excellent' or 'good'. However, 30% of women reported having had an HIV-related illness, 20% reported having been diagnosed with an AIDS-defining illness and 43% reported having a major health condition in addition to HIV/AIDS. The most common additional health condition was hepatitis C with 37% of those women tested, reporting being hepatitis C positive. This figure of 37% actually translates in 25% of women being hepatitis C positive when the whole sample of women is accounted for as only two thirds of women (67%) had been tested for hepatitis C and it is likely that those women considered *at risk* for hepatitis C will have been tested.

Almost all women surveyed have had a Pap smear with 38% of women reporting two or more Pap smear tests in the 12 months preceding the survey. One quarter (25%) of women reported abnormality in their most recent test, which is considerably higher than the Victorian Cervical Cytology Registry, which in 1998 reported 14% of Victorian women having abnormal smears. HIV-positive women and their health care workers need to be aware of the increased possibility of abnormal smears in HIV-positive women.

Treatments

Since the outset of the HIV epidemic both the clinical treatment and the social representation of AIDS has been subject to continual change. Some changes have been relatively slow, such as the gradual shift in social attitudes to AIDS across the whole of Australian society and the reduction in the level of social stigma it attracts. Other changes have been more recent and more rapid, such as the new antiretroviral treatments available since late in 1995. These new treatments have shown major improvements in the prospects for the clinical management of HIV and attendant diseases, at least over the relatively short term for which they have so far been available.

Following the pattern established by the first survey, the second *Futures* survey found significant differences in the use of antiretroviral treatments (ARV) between men and women (see Table 1). Less than two thirds of women (60%) use ARV compared with 75% of men. Women are also less likely to have ever used ARV (76%) compared with men (88%).

Table 1: ARV use by year and gender

	Women	Men	
1997 USING ARV	58% (N=33)	79% (N=658)	$\chi^2=14.00$, $p<.001$
1999 USING ARV	60% (N=52)	75% (N=648)	$\chi^2=9.69$, $p=.002$

More than half (54%) of the women taking ARV experienced side effects and 94% who used ARV in the past also reported experiencing side effects. The majority of women (83%) experienced difficulty taking ARV which includes remembering to take the drugs on time, organising meals around medications, taking medication in public, taking a large number of tablets and transporting medication.

Almost half (42%) of the women believe combination ARV are harmful and a similar number (46%) are unsure whether HIV treatments will stop them dying from AIDS.

One woman who participated in both our survey and a qualitative interview explains the difficulty she has with side effects:

'Once you've been on the medication for so long you get sick of taking the pills -- but you know that you've got to take them, so 'okay I'll take all those pills only because I have to'. But to deal with the diarrhea I have to take another pill to fix that, but I don't want to do that. I'm sick of taking pill after pill'.

[Catherine, 31, diagnosed 1990]

Our analysis also revealed differences in the attitudes of women and men towards ARV treatments as well. In both 1997 and 1999 women were significantly less optimistic than men about ARV meaning better prospects for most people living with HIV/AIDS (1997: 37% versus 59%, 1999: 60% versus 71% – see Figure 1) $p<0.05$. These important differences between women and men tell us that there is a greater uncertainty or distrust among women towards ARV.

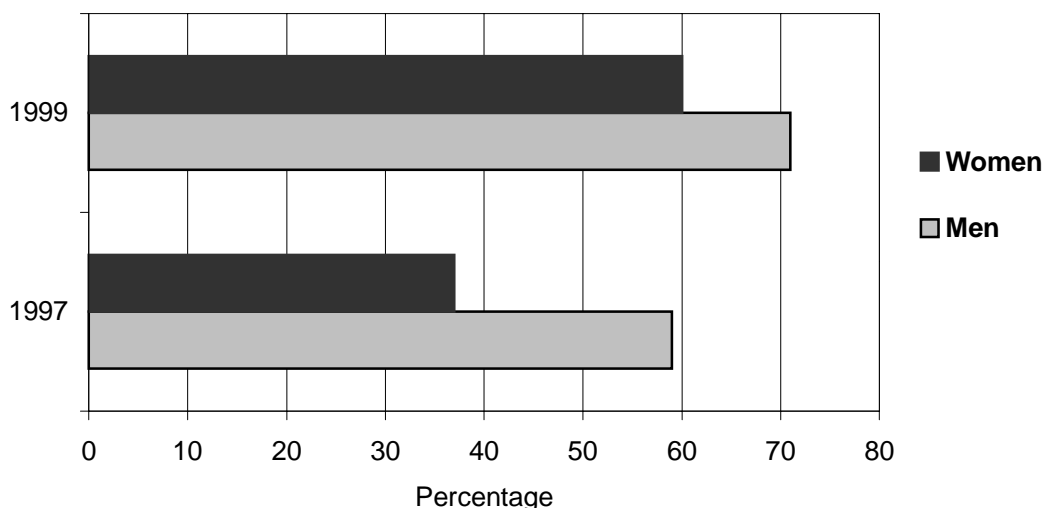


Figure 6: Agreement with the statement 'ARV mean better prospects for most PLWHA' by gender and year

Another woman explains the difficulty she has with side effects and the uncertainty involved in weighing up the pros and cons of taking antiretroviral treatment:

'...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, 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'.

[Jane, aged 46, diagnosed 1993]

It is also important to note that 69% of women reported using complementary therapies to improve their health and well-being and this was significantly different to the 54% of men who also use complementary therapies. Generally complementary therapies included taking vitamins and minerals, massage, meditation, herbal therapies and supplements, acupuncture and traditional Chinese medicine. Use of complementary therapies did not influence women's use of antiretroviral treatment. The vast majority of women (85%) agreed that complementary therapies could improve well-being.

Reproduction/pregnancy

Another issue highlighted by research is the importance of children to women. Most of the women participating in the survey are mothers, and one half (51%) currently have dependent children. The ages of these dependent children ranged from less than one year to eighteen years. Just over half of these children are aged five years and under and thirty percent are two years old or younger.

Nearly twenty percent of the women in our survey are considering having children in the future or actively trying to get pregnant which includes three women who were actively trying to get pregnant at the time of the study and 4 women who want to have a baby in the future, 11 women said they have thought about having children but haven't yet decided and a further six women said they have thought about it but decided that it is too risky. Twenty-two women have had 34 children born since their diagnosis and one woman was pregnant at the time of the study.

Motherhood for many women is a central component of their lives. A woman with a young child said in an interview:

'...my baby (has) made so much of a difference because I have always wanted to have children...my baby's really planned and really wanted...you just wake up every morning [and] you just have to pinch yourself'.

Poverty

Poverty is not mentioned in the title of this paper, however, it is important to acknowledge the number of women living with HIV/AIDS in Australia who are living below the poverty line both in relation to accessing appropriate health care and being able to pay for suitable housing and utilities. Our research found that significantly more women than men are living below the poverty line (46% versus 29%). More than half of the women (53%) rely on government benefits/pension as their primary source of income. Women were significantly more likely than men to report finding it difficult to pay for medical services, co-payments for HIV medication, other prescribed medication, complementary therapies, and support services. These results highlight significant concerns for women living with HIV/AIDS who may be unable to pay for the care and medication they require.

Conclusion

This paper only briefly touches on the results of the HIV Futures studies. However, it demonstrates important differences between women and men and establishes the need for separate analyses and reports. The results presented in this paper clearly show that the women that make up this sample are active health consumers who regularly monitor their own health. Many HIV-positive women in Australia struggle to come to terms with the uncertainty of their illness and the complexity of the choices and decisions they make in relation to their treatments and daily living.

Moreover, the trajectories of antiretroviral treatment usage differ for women. Women are less likely to be using ARV than men and they are more likely to delay the commencement of treatment. Whilst treatments for many women, and indeed people living with HIV/AIDS in general, have improved clinical health and future longevity, the treatments environment is fraught with many difficulties and debilitating side effects.

The importance of children in women's lives is clearly evident. The decisions around having children, disclosure and parenting can be complex. Women must also consider the burden of treatment and the possibility of illness in the context of children.

This data also reveals that almost half of the women surveyed are living below the poverty line. There is no doubt that poverty can be a barrier to health and well-being and this reflects the structural inequalities facing women both in Australian society and globally.

Our research program recognises that positive women's organisations will always struggle for visibility within an epidemic that is experienced predominantly within a gay male culture. The staff and volunteers of positive women's organisations work hard to ensure that treatments, education and support services are appropriate for women and that there is adequate research into women's health issues. We hope that the findings of the HIV Futures provide evidence of the different experience of women living with HIV in Australia and assist organisations and health care workers to achieve adequate health care for HIV-positive women. We also acknowledge that many of the women who contributed to the HIV Futures survey are already using services and plugged into networks of positive women. It is vital that the results of this research reach all women - and especially those who are not connected with organisations. Whilst we recognise that HIV-positive women are not an homogenous group, recognising the commonality of experience between women may help break down isolation and encourage women to use available services. Ultimately we hope that our research contributes to the health and well-being of all people living with HIV/AIDS in Australia. As a final note I'd like to acknowledge the selfless contribution of positive people in Australia who participate in our research and the positive organisations that help us with distribution and dissemination.

'I ALWAYS WANTED TO HAVE CHILDREN': MOTHERHOOD AND HIV-POSITIVE WOMEN IN AUSTRALIA

Oral presentation based on HIV Futures I and II, International Congress on AIDS in Asia and the Pacific (ICAAP) Conference, Melbourne, Australia, October 2001.

Karalyn McDonald.

Abstract

Objectives: This paper explores both quantitative and qualitative data from the national *HIV Futures Surveys* (1997 & 1999) examining the experience of women living with HIV/AIDS in Australia in relation to motherhood. Women make up only 6% of the total number of people living with HIV/AIDS (PLWHA) in Australia and have often been marginalised in both clinical and social research. Becoming a mother is an important part of many Australian women's identities, and this paper explores the importance of motherhood in the context of complexities that HIV-positive mothers face in Australia.

Methodology: The *HIV Futures Surveys* (1997 & 1999) were self-administered questionnaires covering a range of demographic, social, attitudinal and health status issues. Each of these large non-clinical samples of men and women living with HIV/AIDS (1997: n=925 of whom 84 were women; 1999: n=924 of whom 89 were women) represented over 8% of the total estimated population of PLWHA in Australia at the time. In addition to completing the survey, 126 PLWHA, of whom 24 were women, were recruited from the survey samples to participate in in-depth semi-structured interviews.

Results: In both samples female respondents represented approximately 10% of the estimated number of women living with HIV in Australia. Of the female respondents, half had between one and four dependent children, with ages ranging from less than one year to 18 years old. Just over half of these children were aged five years and under and 30% were two years old or younger. In 1999 respondents were asked about their plans to have future children. Nearly 20% of the women surveyed said they are considering having children in the future or actively trying to get pregnant.

The semi-structured interviews explored motherhood in more depth revealing: 1. Disclosure to children and on behalf of children was part of the complexity many mothers face in family and community lives; 2. Women with children emphasised the importance of staying well in order to raise their children; 3. A number of women also discussed their conscious attempts to provide their children with a sense of independence and alternative social support; 4. Many women who were not yet mothers talked about the possibility of pregnancy and the issues related to such a decision.

Discussion: In worldwide literature motherhood is revealed as a desired role and perceived by many as an index for 'successful' womanhood. For many HIV-positive women this is fraught with

uncertainty. Decisions about complicated issues have to be made, often with limited information or support. Despite the cultural differences between women living with HIV in Australia and those in Asia and the Pacific, many HIV-positive women share the experience of motherhood and the complexities that this role can entail as an HIV-positive woman.

Introduction

For many women motherhood is seen as both a natural and rightful role that they will assume at some point in their lives. The existence of an ideology of motherhood, certainly within Western culture, and arguably most cultures, has been confirmed by many researchers and theorists. Irrespective of the disciplines or schools of thoughts that these researchers and theorists subscribe to, the common theme to their work is the recognition that for many women motherhood is seen as an important identity, a significant part of a woman's development and for many the ultimate fulfilment.

Of course being diagnosed as HIV-positive for most women is usually an extremely traumatic event as well as a devastating blow to their sense of self. Not only are these women faced with their own morbidity and mortality but for those women who intended to become mothers their perceived role of motherhood is seen as unobtainable (at least at first). Likewise, when women who are mothers of dependent children are first diagnosed they often believe that they will be unable to fulfil their role as mothers. Common to many women's narratives when recounting their diagnosis is how they first thought of their desire to become a mother and how that dream was suddenly shattered. Despite many women explaining they knew little about HIV/AIDS and assuming imminent death, motherhood was at the forefront of the many losses that women perceive when they are first diagnosed as HIV-positive. So for many women there is a 'double devastation'.

Since 1995, new treatments have improved prospects for the clinical management of HIV and attendant diseases for many people living with HIV/AIDS (PLWHA) in the developed world or for the minority in the developing world who can afford it. More recently the use of Highly Active Antiretroviral Therapy (HAART) antepartum and postpartum to the mother and zidovudine (AZT) mono-therapy to the infant for a brief period has lowered the rates of vertical transmission from HIV-positive women to their babies. For those women who have treatment options, antiretroviral therapy has reduced the risk of vertical transmission from HIV-positive mother to child thereby making it likely that more women will pursue their desired role of motherhood and pregnancy for those who had ruled out the possibility. Additionally, as growing numbers of HIV-positive women live longer and feel better due to the effects of HAART, pregnancy and motherhood have become increasingly important issues.

Method

This paper reports on results from the Australian HIV Futures Studies. Part of these studies includes a survey. The HIV Futures Survey was first conducted at the end of 1997 and again at the end of 1999. It is a national, anonymous mail-back questionnaire, widely distributed through community organisations, the mailing lists of HIV-related publications and various health and social service agencies. The questionnaires covered a range of demographic, social, attitudinal and health status issues.

There were 925 valid responses to the 1999 survey representing over 8% of the total estimated population of PLWHA in Australia. Eighty-nine of these respondents were women, representing 10% of the number of women living with HIV/AIDS in Australia.

The survey includes PLWHA from all Australian regions; from inner urban, suburban and rural areas; men and women; gay and straight. The majority of respondents are gay men, reflecting the epidemiology of HIV in Australia, but particular recruitment efforts were made to ensure representation in the sample of numerically smaller groups such as HIV-positive women, and those infected through injecting and through blood products. The survey covered behavioural and attitudinal aspects of a number of domains including health care and treatments, social and economic life and sexual practice.

In addition to completing the survey, 126 PLWHA were recruited from the survey samples to participate in in-depth semi-structured interviews. Twenty-four of these interviews were with women.

Results

The HIV Futures Studies I and II revealed a number of significant differences between men and women in the experience of living with HIV/AIDS in Australia including the issues of child bearing and rearing. Half of the sample of women had dependent children ranging in age from less than one year to 18 years. Just over half of these children were aged five years and under and almost one third were two years old or younger. This study also found that nearly 20% of the women were considering having children in the future or actively trying to get pregnant. Twenty-two women had had children born since their diagnosis and one woman was pregnant at the time of the study.

The in-depth semi-structured interviews conducted with women revealed just how important the role of motherhood is. Although the issue of motherhood was not the central focus of the study, it was notable that most women discussed various concerns and issues around choices of having children as an HIV-positive woman. For most of these women, children were an important part of their life.

Although today in Australia, HIV-positive women perceive that they have more choices in relation to having children, once women are mothers they are faced with some very complex issues in relation to parenting and their HIV status.

This paper will present four themes that were identified from the data.

A job to do

Almost all of the women who were mothers interviewed emphasised the importance of staying well in order to raise their children. This was particularly so if the woman's child or children were not yet at least in their teenage years. These women often spoke of their sense of future in relation to their children and their obligations as mothers. Obviously this entailed living as long as possible. Melissa was resolute when she told me:

'I want to be here for my kids to grow up. And I am determined that I will be'.

A number of women believed no one would be able to do the job as well as they could. Jessica did not think anyone else could fill her shoes:

'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'.

For some women this resolve for longevity meant that they refused to focus on their HIV-infection. Women talked about not making HIV a central part of their life, putting it to the back of their mind and worrying about it later.

Catherine was one who refused to focus on illness as part of her future:

'But I will never accept what's going to happen. I'm -- there's no way, God, that I'm going to accept and be prepared for that. No. I want to be here for my kids. There's no ifs, buts or maybes. ... I've watched too many people dwell on the fact that they were positive and they just wait. You don't dwell on it. You can't focus your life on it, because it will take control of your life. And AIDS is not your life, your life is your life. Your kids, whatever's around you. AIDS has to take a back seat'.

Protection and autonomy

Women also talked about the difficulty of living with a life-threatening illness and balancing the need to provide their children with love and security and making them independent and able to cope should their mother become ill and then die. Patricia said:

'I think for years, with my kids, it was like I really loved them near me but I was going to die and they're better off if they weren't close to me - it would be easier for them. I found it very hard to be open and loving and caring'.

Janelle also discussed her conscious attempts to provide her child with a sense of independence and alternative social support:

'My main focus for my daughter is to build up the biggest sort of support network for her so that you know, if something does happen to me, she's not just sort of...I haven't been the main person in her life. I like to feel that she can go, she goes and stays with friends, and with family overnight every so often, so I've got to sort of try to break the ties a bit, so that she's not totally reliant on me if anything happens to me, that's my main focus for her'.

Disclosure

Disclosure to children is highly complex and women had many different thoughts about when the right time to do this might be. Some women felt it better if their children didn't know, particularly if

their mother was well. These women tended to emphasise making their children's lives as 'normal' as possible and making HIV as small a part of the woman's life as possible.

Patricia said:

'They know that I am positive - I think, they've had times when their father died - he died four years ago - it was about six months before they were told. So they'd had, like, seven years, I think, without knowing we were positive'.

This was more difficult for those few women who worked in peer support, education or public speaking about living with HIV. These women spoke of the difficulty of balancing their work and the caution they had to exercise in disclosing to prevent any backlash on children – often women asked for their children's permission and talked it over with them first before they tell other people.

Women with young children who wanted their children to know about their HIV status to avoid secrets or having to take treatments in secret, also expressed the caution of telling their children before they could understand the full meaning of the disclosure and the possible implications if their child then chose to disclose:

Allison told me:

'I don't want to tell her that, like him - having AIDS, too soon because then she will go round telling friends you know 'My Daddy had AIDS' [laughs]. She doesn't understand the connotations to having the virus. Just at the moment, you know, 'My Daddy's dead' and that's it'.

Possibility of motherhood

The last theme that I would like to discuss today is the possibility of motherhood. Obviously this area deserves a presentation in its own right but I thought it was important to acknowledge today. Despite the complexities of becoming a mother as an HIV-positive woman almost all of the women who were not yet mothers talked about the possibility of pregnancy and issues related to such a decision.

Arlene, who was only 26 at the time of the interview, revealed the importance of motherhood to her by indicating that she had been thinking about being a mother for a number of years.

'Yes, I would like to be mother, but it's probably one of those grey areas at the moment. I always thought that I would try and go ahead and do it as a single mother anyway ... it just feels a bit too daunting at the moment. I don't know – I'll see what happens'.

This idea that it was a 'grey area' and a daunting decision was common to the women's narratives. These types of narratives demonstrate the importance and need for information about pregnancy and motherhood to be made available to all women who are diagnosed as HIV-positive.

Conclusion

This paper only touches on the desires of women to become mothers and the complexities they face both in the pursuit of motherhood and then as an HIV-positive mother. Of course the issues become even more complicated for those mothers of HIV-positive children.

In literature worldwide motherhood is revealed as a desired role and perceived by many as an index for 'successful' womanhood. Most of the women interviewed for this project revealed that motherhood was an integral part of their identity.

However, for many HIV-positive women this is fraught with uncertainty. What I have presented here are only some of the issues, decisions and strategies that women consider in their role as mothers. The decisions of when and if to have a child, disclosure to their child or children as well as the provision of social support networks are complex and difficult for many women. Clearly, women in Australia perceive that there are more choices available to them with regard to parenting and access to antiretroviral therapy. However, women still need care and support as well as information to help them to make these decisions and care for their children.

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