

Just gettin' on with my life
without thinkin' about it:

The experiences of
Aboriginal people in Western
Australia who are HIV positive



**Just gettin' on with my life
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Aboriginal people in
Western Australia who are
HIV positive**

This report is dedicated to

'Auntie'

the Aboriginal Health Worker who has given so much to Aboriginal people who are HIV positive. The lives of many have been immeasurably improved by her wisdom, care, selflessness and commitment.

Artwork by Deborah Bonar, Aboriginal graphic designer.

Title: A new day, living life to the fullest.

In the cover artwork, the pindan base is the land. The figures represent Aboriginal men and women telling their stories about living with HIV, waking up to a new day and looking forward to living life to the fullest.

The four waves represent links between Aboriginal people, their country, culture, families and communities, where they get love and support that helps them stay healthy.

The track and footprints symbolise Aboriginal people travelling round the familiar places of their mob and traditional healing places. The white dots around the tracks represent health services and medicines.

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ABBREVIATIONS USED IN THIS REPORT

| | |
|---------|--|
| ACCHO | Aboriginal Community Controlled Health Organisation |
| AFAO | Australian Federation of AIDS Organisations |
| AHW | Aboriginal Health Worker |
| AIDS | Acquired Immune Deficiency Syndrome |
| AMS | Aboriginal Medical Service |
| ANCAHRD | Australian National Council on AIDS, Hepatitis C and Related Diseases |
| ARCSHS | The Australian Research Centre in Sex, Health and Society |
| ASHM | Australasian Society for HIV Medicine |
| GP | General Practitioner |
| HIV | Human Immunodeficiency Virus |
| IASHC | Indigenous Australians Sexual Health Committee |
| IDU | Injecting Drug User |
| IGCAHRD | Inter-governmental Committee on AIDS, Hepatitis C and Related Diseases |
| KEMH | King Edward Memorial Hospital |
| MSM | Men Who Have Sex with Men |
| NAHSWP | National Aboriginal Health Strategy Working Party |
| NCHECR | National Centre in HIV Epidemiology and Clinical Research |
| NCHSR | National Centre in HIV Social Research |
| NT | Northern Territory |
| OATSIH | Office for Aboriginal and Torres Strait Islander Health |
| RN | Registered Nurse |
| RPH | Royal Perth Hospital |
| SHBBVP | Sexual Health & Blood-borne Virus Program |
| STI | Sexually Transmitted Infection |
| UNICEF | United Nations Children's Fund |
| UNAIDS | Joint United Nations Program on HIV/AIDS |
| WA | Western Australia |
| WAAC | Western Australian AIDS Council |
| WAACCHO | West Australian Aboriginal Community Controlled Health Organisations Inc |
| WAAHIEC | Western Australian Aboriginal Health and Information Ethics Committee |
| WACHAS | Western Australian Committee on HIV/AIDS and Sexually Transmitted Diseases |
| WHO | World Health Organisation |

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HIV infection in Aboriginal people has largely been invisible up to now. We thank the research participants who gave of their time and selves, opening their hearts and sharing their stories with us. They overcame their fears to share their hopes and experiences in living with HIV. This research could not have taken place without their bravery and trust. It is our earnest hope that the findings of this research will help improve their lives and those of others who have been infected with HIV.

While this research represents the experiences of twenty research participants only, their experiences resonate with those of other Aboriginal people in Western Australia who are HIV positive. Many of the issues they raise are common to non-Aboriginal people living with HIV.

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Steering Committee

Dawn Bessarab (Department of Justice), Chantelle (Community Member), Clyde DuBois, Sally Rowell, Gail Jones (Western Australian AIDS Council), Jim Morrison (WAACCHO), Rani Param (Office for Aboriginal and Torres Strait Islander Health), Rosemary McGuckin, Donna Schultz, Cyril Hayes (Department of Health WA), Kate Turner, Alison Cain, Susan Stewart (Royal Perth Hospital).

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EXECUTIVE SUMMARY

This research was prompted by the “*Mapping Indigenous Risk Workshop*” held in July 2001, when it was noted that there had been almost no research into the experiences of Aboriginal people who are HIV positive, or their access to health services. Western Australia has the highest proportion of notifications of Australian Aboriginal people who are HIV positive, with approximately one-third of the national total. This research provided a means of recording their experiences and identifying their needs for a wider audience, including policy makers and service providers.

From a total of forty-four HIV positive Aboriginal people known to be living in Western Australia at the end of 2002, twenty were interviewed between February and September 2003. Research participants were asked to discuss their experiences of initial diagnosis, coping strategies, social support, disclosure, discrimination, HIV and pregnancy, access to health and HIV services, and the physical, emotional, psychological, social and economic impact of HIV on their lifestyles. Interview data was coded around identified themes and the data was de-identified to protect the confidentiality of the participants.

Research participants were found to be younger; more likely to be female; heterosexual; living in rural areas; dependent on government welfare benefits; and to have considerably less contact with HIV/AIDS organisations, positive networks or publications, than other Western Australian people who are HIV positive, or other Aboriginal and Torres Strait Islander people in Australia who are HIV positive.

Few research participants accessed HIV/AIDS organisations. Although centralisation of these services in the Perth metropolitan area is a barrier to access for rural residents, few metropolitan participants accessed those services either, as they were generally not perceived as user-friendly or culturally appropriate for Aboriginal people.

There was a high level of satisfaction with HIV health services, with the most highly regarded services providing an informal, holistic, confidential, client-centred, user-friendly approach.

Expertise has been developed in one rural health service in providing management of HIV, including HIV health promotion and prevention programs to the Aboriginal population. The service has been instrumental in providing antenatal support and health care to Aboriginal women who are HIV positive. Of the sixteen female participants in this study, nine have had twelve live births since diagnosis. None of the babies were positive.

A common theme identified from participants’ responses was concern for young people who may be sexually active from an early age without being aware of the negative consequences, namely HIV and other sexually transmitted infections and early teen pregnancy. Many participants recommended having Aboriginal positive speakers to educate Aboriginal communities about living with HIV, by telling their stories.

Many of the research participants' experiences in living with HIV are similar to the experiences of any other person living with HIV in Australia. What distinguishes this population is the additional burden of economic disadvantage: lack of employment opportunities, lack of material resources, and living with HIV in small rural or remote communities where there is a lack of privacy.

National surveys of HIV positive people have not captured the experiences of this population and due to their social and geographic isolation the HIV epidemic in Aboriginal people in Western Australia has been largely invisible. This research provides a unique insight into HIV infection in Aboriginal people in Australia, particularly women, and people who live in rural or remote areas.

Specific recommendations are as follows:

Recommendation 1

Establish an HIV positive Aboriginal speaker's program. This will require the provision of training in peer support and public speaking to Aboriginal people who are HIV positive. The aims of the program include making HIV visible to Aboriginal people, providing community education and leadership about HIV and promoting respect and empathy for those who are HIV positive.

Recommendation 2

Introduce, through consultation with Homeswest and Centrelink in Perth, a mechanism by which processing of applications for accommodation and Disability Allowances can be done centrally, so that individuals in rural areas are not required to disclose their HIV status to local staff.

Recommendation 3

Ensure social support for HIV positive Aboriginal women who are relocated for antenatal care and delivery. Where women are transferred to Perth prior to confinement, assistance with transport and accommodation costs is likely to be required for a partner or close relative to accompany them.

Recommendation 4

Broker changes to the clinical service arrangements provided by one major HIV specialist outpatient clinic based upon the feedback of Aboriginal patients. A priority is to shift the emphasis from assessing the patient's need and response to drug treatments, to managing the whole patient in the context of their personal, social and community life. Treatment services must provide a culturally secure, confidential and holistic service that meets patients' needs in a non-alienating environment.

Recommendation 5

Establish communication structures to reduce social isolation, by enabling confidential and anonymous contact between Aboriginal people who are HIV positive.

Recommendation 6

Facilitate a range of appropriate and user-friendly HIV/AIDS information and support services, including social activities, to Aboriginal people in metropolitan and rural areas who are HIV positive.

Recommendation 7

Increase and sustain the delivery of quality, Aboriginal-friendly sexual health and blood-borne virus health promotion and prevention programs. Programs must acknowledge and cater to Aboriginal diversity and include a range of non-print media. Age-appropriate programs for youth should include substance use as a risk factor and should be delivered both within and outside of school settings.

Recommendation 8

Ensure that sexual health and blood-borne virus program development and delivery are supported by carefully selected, skilled, sexual health educators. It is imperative that high priority is given to ongoing, quality training of Aboriginal Health Workers, Health Promotion Officers and Youth Workers in sexual health.

The research findings and recommendations will be forwarded to the WA Indigenous Sexual Health Committee and the WA Committee on HIV/AIDS and Sexually Transmitted Diseases (WACHAS), with a request that they work towards implementing the recommendations, and adopt a monitoring role regarding the outcomes.

1. INTRODUCTION

This research is the first study of the experiences of Aboriginal people in Western Australia who are living with the Human Immunodeficiency Virus (HIV). It was funded by the Office for Aboriginal and Torres Strait Islander Health and the Department of Health Western Australia.

The aims of the research were:

- To enable Aboriginal people who are HIV positive and who wished to do so, to record their experiences for a wider audience including policy makers and service providers.
- To collect information that can be used to improve the quality of life of Aboriginal people with HIV.
- To provide knowledge that may reduce the social and health impact of HIV in the Aboriginal community.
- To increase knowledge of the needs of Aboriginal people who are HIV positive and thereby to reduce any barriers which prevent access to health care.
- To increase understanding of ways that health providers can more effectively respond to HIV in Aboriginal communities through education, prevention and treatment services.
- To develop a partnership between Aboriginal and non-Aboriginal researchers and to encourage Aboriginal interest in social research.
- To develop recommendations that may improve the care of Aboriginal people who are HIV positive, and assist with the prevention of transmission.

Terminology

Although it is recognised that there are two Indigenous populations in Australia, namely Aboriginal and Torres Strait Islanders, this research deals with Aboriginal people and Aboriginal communities in Western Australia. It is acknowledged that the literature reviewed and the research population studied may include Torres Strait Islanders, however this report will refer to Aboriginal people and communities unless an article referred to specifically deals with the Torres Strait Islander population.

The phrase “People living with HIV/AIDS” is widely used in research literature and in the mainstream affected community in Australia. The Aboriginal members of the Research Steering Committee and Reference Group advised that this terminology did not accurately describe the research population, as in the Aboriginal community, the term could be interpreted to include the carers and families of individuals infected with HIV. To avoid ambiguity and to precisely define the research population, the term “Aboriginal people who are HIV positive” has been used in this study.

2. BACKGROUND TO RESEARCH

The epidemiology of HIV infection in Western Australia is provided in more detail in Appendix 1, and only a brief overview is provided here.

Once HIV testing became available, HIV diagnoses initially occurred only occasionally in Aboriginal people in Western Australia and these isolated cases were mainly attributed to homosexual transmission or injecting drug use. In the mid 1990s, a cluster of related infections that were mainly associated with heterosexual transmission was identified in a rural area. From this time, Aboriginal HIV diagnoses have occurred consistently every year, with occasional peaks where Aboriginal people have been over 20% of all Western Australian HIV diagnoses in that year. Infections have occurred in Aboriginal people living in rural, remote and metropolitan regions. The proportion of the population that is Aboriginal is small, but their rates of infection now exceed those of non-Aboriginal people, and the epidemiology of infection is quite different. In the period 1996–2002, Aboriginal people have accounted for 12% of HIV notifications in Western Australian residents, 6% and 39% of the notifications in Western Australian males and females respectively.

Cumulatively, from 1983–2002, there were slightly more diagnoses in Aboriginal women than Aboriginal men (32F, 28 M). Comparatively, the rates in Aboriginal women are particularly high, with a rate ratio 18 times that of non-Aboriginal women. Women have been infected across a wide range of ages, with a number infected in late adolescence (15–19 years) whereas Aboriginal male infections have overwhelmingly been diagnosed in 30–39 year olds. Whereas 74% of non-Aboriginal infections have occurred in men who have sex with men (68% MSM + 5.5% MSM/IDU), 68% of infections in Aboriginal people are a result of heterosexual transmission, with only 20% in MSM (10% MSM + 10% MSM/IDU).

Many diagnoses have been made as a result of contact tracing, but it is of concern that “sporadic” cases have also been identified, suggesting unidentified infections. The high rates of sexually transmitted infections occurring in Aboriginal people provide further reason for concern about the upward trend in HIV infections in Aboriginal people in Western Australia.

At the end of 2002, there were forty-four Aboriginal people, seventeen males and twenty-seven females living in Western Australia who had been diagnosed as HIV positive. Twenty-three resided in the metropolitan area and twenty-one in rural areas.

Information regarding the incidence and distribution of HIV in the Aboriginal population in Western Australia has not been widely available, due to the sensitivity of sexual health issues, the potential for adverse publicity and to protect the confidentiality of individuals living with HIV in Aboriginal communities. Considerable expertise has been developed in some areas to respond to HIV in this population including health promotion and prevention, health service provision, care and support, but little of this has been published.

National responses to the HIV Epidemic

The incidence of HIV/AIDS in Australia has remained low with awareness of HIV occurring before there was an established epidemic. There was early mobilisation of the gay community with their involvement in HIV prevention, education and health promotion. In addition, screening of blood supplies, needle and syringe programs and promotion of safe sexual practices were features of the national response (Commonwealth Department of Health and Aged Care 2000; Guthrie et al. 2000).

The Ottawa Charter for Health Promotion, which was developed in 1986 (AFAO 1992), formed the basis for Australia's first National HIV/AIDS Strategy, which was endorsed by the Commonwealth Government in 1989 after extensive consultation with community groups, the medical profession and government authorities (Wall et al. 1992). A national strategic approach, fostering partnerships, non-partisan political support, health promotion and harm minimisation, and the involvement of affected communities, have been core elements of Australia's response to HIV/AIDS (Commonwealth Department of Health and Family Services 1996). Australia's swift and innovative response to the epidemic has gained approval worldwide.

The fourth (and current) National HIV/AIDS Strategy has broadened to include linked strategies with the National Hepatitis C Strategy and a nationally coordinated approach to sexual health within the context of a national communicable diseases framework (Commonwealth Department of Health and Aged Care 2000). Preventing the emergence of an HIV epidemic among Aboriginal and Torres Strait Islander people is a priority of the current strategy.

Aboriginal and Torres Strait Islander people have been thought to be at particular risk of HIV infection since the early years of the epidemic. This belief led to the formation of a Working Panel specifically to focus on the issues involved with Aboriginal people and HIV/AIDS and to contribute to the first National HIV/AIDS Strategy of 1989 as one of six expert panels (Commonwealth Department of Health and Family Services 1997). Aboriginal and Torres Strait Islander communities were noted as a priority group regarding funding for prevention, education, treatment and care programs (Commonwealth Department of Community Services and Health 1989a and 1989b).

The National Aboriginal Health Strategy Working Party was established in December 1987 and produced *A National Aboriginal Health Strategy* (NAHSWP 1989). The Working Party proposed a more holistic model of health delivery, more control over all aspects of life and greater autonomy for Aboriginal communities. They defined health as:

Not just the physical well-being of the individual but the social, emotional and cultural well-being of the whole community. This is a whole-of-life view and it also includes the cyclical concept of life-death-life (NAHSWP 1989:x).

The National Aboriginal Health Strategy placed community-controlled health organisations at the forefront of responses to sexual health. The strategy directly influenced Aboriginal health policy and subsequently, the first National Indigenous Australians' Sexual Health Strategy 1996–97 to 1998–99 (Commonwealth Department of Health and Family Services 1997), which linked to and complemented the third National HIV/AIDS Strategy (Commonwealth Department of Health and Family Services 1996).

The Implementation Plan for 2001/02 to 2003/04 of the National Indigenous Australians' Sexual Health Strategy (Commonwealth Department of Health and Ageing 2002), continues to link with mainstream HIV/AIDS and Hepatitis C Strategies, while keeping the core values of autonomy, community control and a holistic view of health.

Recurring theme: The “sense of impending disaster”

In 1988 sensationalised media reports of AIDS in Aboriginal and Torres Strait Islander communities (Walker 1989; Townsville Bulletin 1988) raised concerns that the virus would infect and decimate a large section of that population. This resulted in the “scapegoating” of a particular Aboriginal community, and the identification of infected individuals (Neilsen and Young 1993). The damaging impact of media reports understandably led to media protocols for reporting on Aboriginal sexual health matters, which would keep comments as general as possible, with no mention of specific places, communities or individuals (Commonwealth Department of Health and Family Services 1997).

It was noted in the second National HIV/AIDS Strategy that although HIV infection rates were comparable for Aboriginal and non-Aboriginal people, the higher rate of sexually transmitted infections increased the potential of HIV transmission in the Aboriginal population (Commonwealth Department of Human Services and Health 1993). An evaluation of the second National HIV/AIDS Strategy raised concerns of an emerging HIV epidemic among Aboriginal and Torres Strait Islander communities, and again highlighted the high rates of sexually transmitted infections both as a marker of high risk behaviour and increasing the likelihood of HIV transmission (Feachem 1995).

The “sense of impending disaster” (Neilsen & Young 1993) in relation to the possibility of a large scale HIV epidemic in Aboriginal and Torres Strait Islander people has continued to surface regularly (Hollows 1992; Bowden & Patel 1993; Philpott 1993; Bowden et al. 1994; Douglas 1995; Wooldridge 1995).

HIV research, health promotion and prevention in Australia

In 1987, the Australian government launched the first of its public education campaigns, the “Grim Reaper” television commercial, designed to raise community awareness of AIDS and to educate the public that HIV/AIDS is not confined to gay males. In 1988, further commercials, the “Beds” and the “Feet”, were released to raise awareness of risk factors and promote the use of condoms. Campaigns including “Condoman” were launched to promote the use of condoms in Aboriginal communities (Hill 1996; ANCAHRD 2002).

In the first National HIV Strategy in 1989 it was emphasised that all members of the community were at risk of HIV infection. In addition to the general community, specific groups were targeted for education campaigns. These included men who have sex with men, women, sexually active young people, sex workers, injecting drug users, Aboriginal and Torres Strait Islanders, people of non-English speaking backgrounds and people living with HIV/AIDS (Commonwealth Department of Community Services and Health 1989b).

The majority of new HIV infections in Australia continued to result from men having sex with men. In the absence of tangible proof of sick people in their communities, the messages transmitted through education campaigns were easily dismissed by the general public and by Aboriginal people (Bradford et al. 1994). HIV/AIDS continued to be perceived as a health problem mainly for gay white males. In Aboriginal communities where the incidence of HIV was low, it was difficult to maintain community interest (Read 1991).

In 1989, *AIDS – a story in our hands to share* a health promotion and education flipchart was developed in the Northern Territory by Aboriginal people (Northern Territory Department of Health 1989). In 1991, Commonwealth funding was provided for Aboriginal projects such as the *Turtle Dreaming Project* at Palm Island, which involved trialling a model for the care and support of HIV infected people in a remote and isolated area. The Redfern Aboriginal Medical Service carried out a similar project in an urban setting (Commonwealth Department of Health, Housing and Community Services 1992). Some of the early Aboriginal initiatives received both national and international acclaim (Read 1991).

Funding was also provided for the First National Aboriginal HIV/AIDS Conference, held in Alice Springs in 1992 under the banner of *Everybody's Business* (Behrendt 1992). The conference aimed to discuss issues such as unprotected sex and needle sharing in prisons (Morris 1992), homosexuality and bisexuality in Aboriginal communities (Smith 1992), remote communities and HIV/AIDS (Reid 1992) and education and prevention in Aboriginal communities (Close 1992).

The mobilisation of gay males at the beginning of the epidemic in Australia and their participation in HIV/AIDS strategies led to the provision of services, such as AIDS Councils, for those affected. For example, in 1985, the gay community established the Western Australian AIDS Council (WAAC 2003). However, AIDS Councils were not perceived as being user-friendly for Aboriginal people, nor were they perceived as having awareness of Aboriginal culture (AFAO 2002).

“Anwernekenhe”, the First National Aboriginal and Torres Strait Islander Gay Men and Transgender Sexual Health Conference was held in the Northern Territory in 1994. Sponsored by the Commonwealth for gay men and “sistergirls” (men living as gendered women) under threat of HIV/AIDS, it was possibly the first forum of its kind in the world (AFAO 2002). One of the forty-five recommendations from the conference was that funding be provided to develop and implement a national strategy to address the needs of this group (Anwernekenhe Conference Committee 1994).

The conference was the catalyst for the formation of a national identity group for Aboriginal gay men and sistergirls (Lee & Moore 1998). The AFAO Indigenous Gay and Transgender Steering Committee was formed to monitor and pursue the goals identified at the conference, including the establishment of the National Indigenous Gay and Transgender Project and the overseeing of the National Consultation Report and Sexual Health Strategy (AFAO 1998).

The Consultation Report and Sexual Health Strategy (Lee & Moore 1998) was launched in 1998 at the “Anwernekenhe II” conference in Queensland and endorsed by delegates (AFAO 2002). The First National Indigenous Sistergirl Forum was held in Queensland in July 1999 (Costello & Nannup 1999) and “Anwernekenhe III”, the Third National Indigenous Gay, Sistergirl and Transgender HIV/AIDS and Sexual Health Conference, was held in Melbourne in May 2002. For the first time, HIV/AIDS and sexual health organisations, both Aboriginal and non-Aboriginal, were invited to attend (AFAO 2002).

These conferences and forums provided an important mechanism for identifying issues such as alcohol abuse and sexual assault of youth by older males, issues around Aboriginal people living with HIV/AIDS and issues around gay identity formation in young people. They were also important in working towards addressing the sexual health needs of Aboriginal gay, sistergirl and transgender people, establishing the structures and processes to carry out research and to achieve key objectives of their Sexual Health Strategy.

Research has been an important facet of Australia’s response to HIV/AIDS. Four major research centres attached to universities have been established for epidemiological, clinical, virological and social/behavioural research (Shaw et al. 2001).

Research has been carried out into injecting drug use in Aboriginal communities in Brisbane (Larsen et al. 1999), Darwin (Roberts & Crofts 2000), Melbourne (Lehmann and Frances 1998), South Australia (Lane 1993; Holly and Shoobridge 2002) and in Western Australia (Gray et al. 2001). A *Report to IGCAHRD from the Working Party on Injecting Drug Use and Blood-Borne Viruses in Indigenous Communities* was compiled in Western Australia with input from stakeholders (2003). There has, however, been very little published research specifically relating to HIV in Aboriginal people or communities.

HIV health education, promotion and prevention campaigns have been informed by research findings. In Western Australia, regional health promotion strategies have supported the writing and performance of plays such as *No Prejudice* (Mellick 1991) and *Love Life* (Bonar et al. 2000), to educate Aboriginal audiences about HIV/AIDS.

Aboriginal community-controlled health organisations have developed local resources, with the Aboriginal and Islander Health Worker Journal listing forty such resources in a special edition in 1996 (cited in Shaw et al. 2001:3). Aboriginal and Torres Strait Islander sexual health promotion initiatives have been described and documented in New South Wales (Smith et al. 1999). Health promotion/educational resources have been developed in local regions for Aboriginal Health Workers dealing with HIV/AIDS. Others have been developed for health professionals working with Aboriginal people, such as the education and counselling guide *Talking about HIV/AIDS in the Kimberley* (Lowe 1998).

A report on Aboriginal and Torres Strait Islander people living with HIV was published following the HIV Futures II Study, in which nine hundred and twenty-four people living with HIV/AIDS responded to a survey in 1999 (Willis et al. 2002). Of the respondents, twenty-three identified themselves as Aboriginal or Torres Strait Islanders, which provided a snapshot of their experiences. The authors, however, warned against drawing general conclusions from the results due to the small number in the sample and the fact that the questionnaire was designed for the broad community of people living with HIV/AIDS in Australia and not specifically for Aboriginal and Torres Strait Islander people. Eighteen of the twenty-three respondents identified as male and four as female (one did not identify their sex). Twelve identified as gay or lesbian, five as heterosexual and six as bisexual. Ten of the males indicated that they were infected through male to male sex; three indicated homosexual contact and injecting drug use; and three did not indicate the likely mode of transmission. Seven people, including the four female respondents, cited heterosexual contact. The average age of the Aboriginal and Torres Strait Islander respondents was younger than the rest of the sample (37.9 versus 42.4). Age at HIV diagnosis was also younger than the rest of the sample (27.9 versus 33.6). Only one of the twenty-three Aboriginal respondents was from Western Australia.

In 1997, the Western Australian AIDS Council commissioned an HIV Services Access Project for people living with HIV/AIDS in rural Western Australia. This involved surveying rural doctors regarding their views on the needs of patients who were living with HIV/AIDS. The patients themselves were not surveyed (Portsmouth & Bennell 1997). Some of the major psycho-social needs identified by doctors were fear of disclosure; lack of confidentiality in a small community; stigma of HIV/AIDS; and isolation from support, information, services and peer support from other people living with HIV/AIDS.

Those doctors who had treated Aboriginal patients who were HIV positive listed the following additional factors which affected this group:

- Being in denial about their illness
- Coming from a socially marginalised group
- Having low literacy/general educational levels
- Lack of awareness about the significance of their diagnosis
- Lack of culturally appropriate service
- Lack of culturally appropriate service providers
- Lack of culturally appropriate educational materials and teaching techniques
- Lack of culturally appropriate support
- Being without a telephone or mailing address
- Lack of cool storage or fridge for medication
(Portsmouth and Bennell 1997:49).

The Western Australian AIDS Council recommended that a follow-up study of rural and urban people living with HIV/AIDS be conducted.

Some studies were not published or were not publicly available, due to the sensitivity of information regarding the incidence of sexually transmitted infections in particular locations, or the concern that individuals or Aboriginal communities may be publicly identified by undesirable media attention. One such study in Western Australia evaluated a program developed in the regional area of special need, to provide care, treatment and support for Aboriginal people who are HIV positive. Although the quality of the program was evaluated, there was no direct client contact to assess the level of “consumer satisfaction” (Pitman 2001:21).

Two subcommittees of ANCAHRD, the Indigenous Australian’s Sexual Health Committee and the Clinical Trials and Research Advisory Committee held a “*Mapping Indigenous Risk Workshop*” in July 2001. Prior to the workshop, a background paper was prepared to inform and stimulate discussion and to identify gaps in research. It was noted that there was almost no research into the experiences of Aboriginal and Torres Strait Islander people who are HIV positive or their access to health services (Shaw et al. 2001).

The “*Mapping Indigenous Risk Workshop*” considered social research on the experiences of Aboriginal Australians to be a high priority. The high proportion of HIV positive Aboriginal people who were living in Western Australia and the perception by medical providers that at least some of them were now ready to tell their stories, encouraged discussion of the possibility of such research being undertaken in Western Australia.

A proposal to conduct social research into the experiences of Aboriginal people who are HIV positive was submitted to the WA Indigenous Sexual Health Committee in 2001. The committee fully supported the proposal.

Funding was provided by the Office for Aboriginal and Torres Strait Islander Health and the project commenced in November 2002. This report is the outcome of this social research project.

3. METHOD

Phase 1: Developing the aims & design of the research project.

In August 2002, key stakeholders were invited to participate in a preliminary discussion to map out the broad project design and to establish a Steering Committee. Representatives from Curtin University, the Department of Indigenous Affairs, the Aboriginal and Torres Strait Islander Commission, the WA Aboriginal Sexual Health Committee, Royal Perth Hospital, the Office for Aboriginal and Torres Strait Islander Health, the Western Australian AIDS Council, the Kulunga Research Network and the Department of Health Western Australia, were among the nineteen people who attended the meeting.

Aboriginal people were consulted in developing the aims and design of the research and at each stage of the research process. This included collaboration with Aboriginal people who are HIV positive and the Aboriginal health providers who work with them. To ensure meaningful input at the early stages of the project, it was decided to delay submission of the application to the Ethics Committee until adequate consultation with Aboriginal people who were HIV positive had occurred and their input had been incorporated into the research design.

To achieve this, an Aboriginal researcher met with five rural Aboriginal women who were attending a Positive Women's Retreat, to consult with them regarding the aims of the research project. An Aboriginal man from the metropolitan area who is HIV positive also had input into developing the aims of the research project, ensuring that input was received from male and female perspectives, as well as rural and metropolitan.

The research was initially framed as a qualitative, comparative study of the experiences of people living in urban and rural settings. The rationale for this was that in Western Australia, a distinct model of care had evolved for a particular rural cluster of HIV positive Aboriginal people, whereas for other regions, models of care were less developed with services delivered in a less consistent or planned way. The research provided a means of examining experiences with a view to having useful outcomes for Aboriginal people who are HIV positive and for service providers. Framing the research in this way was also a recognition of the diversity which exists within and between Aboriginal communities in Western Australia. In practice, a rural/urban comparison of experiences proved to be an artificial distinction, due to the mobility of the research participants.

Aboriginal people who are HIV positive may experience a range of social, geographic and other barriers to effective health care and quality of life. The extent of these barriers may vary widely depending on location, community attitudes, service accessibility, gender and cultural appropriateness of services, and many other factors. The research provided a means of gauging the extent of any barriers as well as providing the opportunity for participants to tell their story.

A Project Reference Group and a Steering Committee were established, with both groups directly contributing to the research design. The Steering Committee included five Aboriginal members drawn from health and research backgrounds and representation from the HIV positive Aboriginal community.

In addition to having a member on the Project Reference Group, the National Centre in HIV Social Research at the University of New South Wales acted in a consultancy capacity, providing expertise to the research project. The Centre assisted with advice on the methodology of the research. Staff at the Centre also provided intensive training in HIV Social Research to the Senior Research Officer and ongoing advice during the project.

As one of the aims of the research was to increase the capacity and experience of Aboriginal people to undertake social research, it was initially considered preferable to employ an Aboriginal Research Officer. However, there were no Aboriginal applicants for the advertised position and the successful applicant, although not Aboriginal, had extensive experience working with Aboriginal people, including HIV positive Aboriginal people, in rural, remote and metropolitan areas of Western Australia. Her qualifications included a Bachelor of Arts in Anthropology and experience in public health, nursing and in Community Corrections/Justice.

The Senior Research Officer was provided with an Aboriginal mentor, a skilled professional with expertise in qualitative research, who provided ongoing advice and support. Formal mentoring was invaluable for providing technical advice regarding culturally appropriate interviewing; the opportunity to engage in theoretical discussion involving ethical issues; and useful reference materials, particularly regarding cross-cultural research.

An application was submitted to the WA Aboriginal Health and Information Ethics Committee (WAAHIEC) in December 2002. Approval for the research project was granted by WAAHIEC in January 2003. Royal Perth Hospital Ethics Committee, and Fremantle Hospital and Health Service Human Research Ethics Committee subsequently granted approval for the research.

Phase 2: Interview Guide

The interview guide (see Appendix 2) and information sheet were completed after feedback and input from the Reference Group and the Steering Committee. In case any research participants were anxious or distressed after being interviewed, a list of counsellors who agreed to be available was drawn up for each region of Western Australia.

Phase 3: Recruitment strategy

The Senior Research Officer visited clinics at Royal Perth Hospital and Fremantle Hospital to discuss the research with staff and ask them to invite eligible clients to participate. Staff members were given background material and copies of the information sheet.

Information sheets and details of the research were also distributed to staff of the relevant metropolitan and rural Aboriginal Medical Services, rural health services, the Case Management Program, the Western Australian AIDS Council, the HIV/AIDS Pastoral Care Ministry, and individual health professionals including Aboriginal Health Workers and Community and Public Health Nurses.

Participants were recruited into the study for semi-structured interviews via referral from a range of health providers. To be eligible for inclusion in the study, participants had to be Aboriginal, HIV positive and living in Western Australia.

Participants were referred from the following sources outlined in Table 1.

Table 1: Referral sources for research

| Location | Number |
|--|---------------|
| Rural Health Services | 11 |
| Case Management Program | 3 |
| AHW, East Perth Metropolitan Health Unit | 2 |
| Fremantle Hospital | 2 |
| Western Australian AIDS Council | 2 |

Referrals were initially slow, particularly in the metropolitan area, with only six of the twenty research participants coming from suburbs of the metropolitan area.

The remaining fourteen participants were from rural or remote areas. Heat, isolation, client mobility and lack of communications caused extra difficulties in carrying out research in the bush. Visits to remote areas involved travelling long distances over unsealed bush roads featuring flat tyres, and kangaroo, emu and other livestock wandering over the track. Sometimes such journeys resulted in disappointment with the intended participants no longer in the community, or unwilling to participate at that particular time.

Health professionals in the regional area of special need had spent several weeks discussing the research with their clients and recruiting volunteers prior to the researcher's visit. It was tentatively planned that the researcher would interview participants at the local health clinic in town, and at a remote area clinic over a one week period. However, as is often the case with fieldwork in rural or remote areas in Western Australia, plans had to be radically modified.

Some prospective participants were living in one location when travel plans were made, but had moved elsewhere when the researcher visited their community. Others who had agreed to be interviewed, did not keep their appointments, or turned up on a different day when the researcher was elsewhere. By the end of the first week, only two interviews had been completed and two visits to other locations in the region had not yielded any additional participants. The researcher made a round trip of 1,000 kilometres over two days to interview an isolated participant, who changed her mind and decided not to be interviewed after all.

The field trip to the regional area of special need had to be extended by four days and a second trip was made to the same region approximately two months later enabling several more interviews to be recorded. A total of eleven interviews were conducted there. Staff at the local health clinic provided a great deal of assistance to the researcher. They discussed the research with their clients, arranged interviews, accompanied the researcher on home visits and drove her out bush to visit other communities. The researcher was given an office, accommodation and the use of a vehicle and a computer. Heat, distance and isolation, plus the lack of communication due to the absence of telephones, fax machines and computers in remote areas, characterised parts of the rural research; however, this was balanced by country hospitality and camaraderie.

Unfortunately, there were few referrals from other rural regions. Two participants from other rural areas were interviewed while in Perth attending medical appointments, while a third was interviewed in a metropolitan prison.

Phase 4: Procedure

Practice interviews were held with non-Aboriginal volunteers recruited via the Western Australian AIDS Council. These interviews were not regarded as pre-testing or piloting the interview guide, given the differences in socio-economic and cultural backgrounds between these volunteers and the study group. The practice interviews provided a “dummy run” for the Senior Research Officer in using the tape recorder and in the technical aspects of research interviews and they were very useful for this purpose.

From a total of forty-four HIV positive Aboriginal people known to be living in Western Australia in January 2003, twenty were interviewed between February 2003 and September 2003, consisting of sixteen females and four males. Three participated in a second interview to enable the researcher to obtain further data. Fifteen participants consented to provide taped interviews. Five agreed to have the researcher make written notes of the interview, but not to be tape recorded.

Participants were interviewed in a place of their choosing and field notes were recorded after each interview. Locations included the researcher's office, rural health clinics, participants' own homes, hostels and one occurred in a prison setting.

Interviews generally ranged from forty minutes to one hour. Participants were given a copy of the information sheet to keep. The researcher read through the text of the information sheet and consent form with each participant unless they expressed a preference to read them themselves. Each participant was asked to sign a consent form. Participants were paid \$20 for each interview to cover travel or other expenses.

Participants were asked to discuss the circumstances of their positive HIV result. Interview questions explored their reactions to the diagnosis, coping strategies, circumstances of disclosure of their status to others, instances of discrimination, and the physical, emotional, psychological, social and economic impact of HIV on their lifestyles.

Non-Aboriginal transcribers were selected on the advice of the Aboriginal members of the Steering Committee, to avoid any possibility that the transcriber may recognise a participant's voice and compromise confidentiality. Transcribers were required to sign a confidentiality agreement. Interview tapes were transcribed verbatim and checked for accuracy by the interviewer. Each tape was copied twice. The originals were stored in a locked cabinet with only the Principal Researcher and the Senior Research Officer having access to the interview tapes. Each participant was offered a copy of their tape. Six participants requested and were given their own copy to keep.

The majority of participants were women, some of whom had young children. It was difficult for some women to attend an interview without their children, so they brought the children with them. Conducting an interview with young children present or transcribing interviews with a high level of background noise added another level of complexity to the research. Some of the more difficult interviews had to be transcribed by the researcher, rather than sent to a transcriber.

Research data was de-identified in order to protect the anonymity of the participants. Some participants chose a pseudonym. Those who did not were assigned one. Any data which may identify anyone was omitted.

Later in the research process, the Senior Research Officer visited an Aboriginal Women's Positive Retreat to discuss the research findings and obtain feedback on the draft report. As far as possible, individual research participants were contacted for feedback on the research findings and to give them the opportunity to make changes or corrections to their stories.

4. RESULTS

The names of participants have been changed in order to protect the privacy of individuals who have taken part in the research. Some participants chose their own pseudonyms. Those who did not were assigned one.

Regions and towns have been discussed in general terms only so that Aboriginal communities are not identified.

The interview guide was designed around topics such as coping strategies, social support, disclosure, discrimination, experience of initial diagnosis, HIV and pregnancy, physical and psychological effects of infection, and the experience of living with HIV including the social and economic impact. Interview data was coded around identified themes using NVivo Software. Analysis is grouped under the following headings:

(a) Characteristics of research participants

- Research participants
- Mode of transmission
- Knowledge of HIV prior to diagnosis

(b) Experience of living with HIV

- Experience of diagnosis of HIV
- Coping strategies
- Disclosure
- Discrimination
- Social support
- Economic impact of living with HIV
- Social impact of living with HIV

(c) Fertility

- HIV and pregnancy

(d) Health care and access to HIV information and support services

- Experience of health and wellbeing
- Participants' views of health care provision
- Participants' suggestions for improvements to health services
- HIV Services

(e) Health promotion and education issues

- Participants' suggestions for future education of Aboriginal communities

(a) Characteristics of research participants

Research participants

Twenty research participants were interviewed, consisting of four males and sixteen females. At the time of interview, six were resident in metropolitan areas, thirteen were resident in rural areas, and one was in prison. The latter usually resided in a rural area and was classified as such for the purpose of this study.

Research participants were classified as rural or metropolitan residents according to their usual address at the time of interview. Perth and Fremantle residents were classed as metropolitan, while those from all other regions of Western Australia were classed as rural.

Age at the time of interview ranged from 22 to 54 years, with an average age of 31 years for females, 36 for males.

Age at HIV diagnosis ranged from 16 to 49 years, with an average of 24.8 years for females, 31 for males. Among the females, five were only seventeen years old at diagnosis, while another was sixteen. The year of diagnosis ranged from 1993 to 2002.

Thirteen of the 16 female participants had children, with 9 of the 16 giving birth since diagnosis.

One participant was employed at a Community Development Employment Project, one was dependent on an employed partner, and the remaining 18 were receiving a variety of government benefits, pensions or social security payments.

All participants were literate. All had attended high school, at least to Year 8 level, two had attended post-secondary college or TAFE courses, and one was attending a degree course at university at the time of interview.

Seventeen participants named specific Aboriginal linguistic or skin group affiliation, while 3 identified as Aboriginal only.

The characteristics of research participants are outlined in Table 2 below.

Table 2: Characteristics of research participants

| Sex | Age at interview | Age at diagnosis | Children | Secondary Education | Current partner | Mode of transmission | Address at interview |
|-----|------------------|------------------|----------|---------------------|-----------------|----------------------|----------------------|
| M | 38 | 30 | No | Yr 10 | No | MSM | Metro |
| M | 32 | 22 | No | Yr 8/9 | No | MSM | Metro |
| M | 32 | 31 | Yes | Yr 8/9 | No | H | Metro |
| M | 42 | 41 | No | Yr 10 | No | H | Rural |
| F | 26 | 17 | Yes | Yr 8/9 | No | H | Rural |
| F | 31 | 23 | Yes | Yr 9 | Yes | H | Rural |
| F | 28 | 21 | Yes | Yr 11 | No | H | Rural |
| F | 23 | 17 | Yes | Yr 10 | Yes | H | Rural |
| F | 30 | 29 | Yes | Yr 8/9 | No | H | Rural |
| F | 24 | 17 | Yes | Yr 10 | No | H | Rural |
| F | 25 | 17 | No | Yr 9 | Yes | H | Rural |
| F | 32 | 23 | Yes | Yr 9 | Yes | H | Rural |
| F | 54 | 49 | No | Yr 9 | No | H | Rural |
| F | 28 | 21 | Yes | Yr 11 | No | H | Rural |
| F | 26 | 16 | Yes | Yr 12 | Yes | H | Rural |
| F | 32 | 30 | Yes | Yr 11 | No | H | Rural |
| F | 22 | 17 | Yes | Yr 8/9 | Yes | H | Rural |
| F | 39 | 38 | Yes | Yr 11 | No | H | Metro |
| F | 40 | 31 | Yes | Yr 9 | No | H | Metro |
| F | 36 | 31 | No | Yr 9 | No | H | Metro |

Key to abbreviations:

M=Male;

F=Female

H=Heterosexual

MSM=Men who have sex with men

Mode of transmission

Participants were asked to tell how HIV was passed on to them, how they felt about getting it this way and if they had known they were at risk. Two of the males identified themselves as gay, acquiring HIV via male-to-male sex. The remaining eighteen participants identified heterosexual transmission as the mode of infection. One male and two female participants also reported prior injecting drug use, however in one case this had occurred many years prior to infection; in another, the participant stated he had always used clean injecting equipment; and the third indicated that she had acquired the infection heterosexually. The role of alcohol in reducing inhibitions and control figured in several accounts, as did shock that the person who exposed them did so without disclosing their HIV status.

Participants described a range of emotions ranging from sadness, anger and betrayal, to simply being unlucky.

Denise: It was sex. Not using condoms.

Interviewer: How do you feel about getting it this way?

Denise: Sad.

Interviewer: Did you think you were at risk of getting it?

Denise: No.

Kimberley: ...I had my ex-boyfriend around and that's why I got the gonorrhoea.

Interviewer: And is that where you got the HIV from as well?

Kimberley: Mmm...The same person.

Krysta: Oh I had sex with this fellow and I didn't even know that he had HIV. He didn't tell me.

Frances reported that she was infected when she exchanged sex for alcohol.

Frances: That white bloke. He give it to me. He give me drink for that, you know? I got a shock. That man gone give me that. I told her [*Community Health Nurse*] that then, I told her if I see him, I'll shoot him.

Carole and Carmen mentioned excessive alcohol consumption as a risk factor in sexual behaviour.

Carole: Probably through sex.

Interviewer: How do you feel about getting it that way?

Carole: Don't know. Don't know who would have done it, I was too drunk. Too drunk and stupid.

Interviewer: So you didn't have a regular partner at that time?

Carole: No.

Interviewer: Did you think you were at risk of getting it then?

Carole: Yeah.

Carmen: Um, well I went with one bloke, he didn't tell me about himself. At the time I was a little bit drunk. And I started getting sick and things, but I didn't catch on that I had it.

Some participants expressed hurt or anger over acquiring HIV from someone they trusted.

Karina: I was angry at him. I'm still angry at him. He should have told me. That's wrong to do that.

Interviewer: Did you think you were at risk of HIV?

Karina: No, I didn't. I trusted him and he was muckin' around with every other womans.

Interviewer: You didn't muck around?

Karina: No. I didn't do that.

Pauline: I approached that person who gave it to me. Told him he destroyed my life...he gave me this 'ere. He never talks much at all to me. He was the first bloke I been with. Had the miscarriage by him. We broke up. He was seeing a few other girls then he come back to me. I didn't know he's affected. Now I got to do this for the rest of my life.

Bonnie: Oh it really hurt me, it got me so wild, he could have told me.

Interviewer: Did you think you were at risk?

Bonnie: Yeah, I knew I was at risk. Well he was going on with a lot of womans, you know. And I was thinkin' very hard, shall I go with him or not, you know. But a one-night stand, it just sorta changed my life and that's no good. Sometimes I feel like cuttin' his throat too [laughs].

Nick was surprised when he was diagnosed HIV positive. As a gay male, he knew that he belonged to a high-risk group, however he believed his sexual activities were low risk.

Nick: Not using enough lubricant with a condom and the condom broke, or else it was a defective condom or something like that. Either that or one that expired. I have no idea. All we know is we used a condom and it broke and we weren't really up to date on the proper use of it.

Interviewer: Would you say you didn't think you were taking risks or anything, you know, you were actually looking after it as best you could?

Nick: Yeah, that's why it was a surprise when it came back and it turned out positive.

Interviewer: How do you feel getting it this way?

Nick: Unlucky. [Laughs]. Other than that, I suppose it's the only way you can put it. Whichever way you get it, it doesn't matter, you've got to deal with it.

Knowledge of HIV prior to diagnosis

Participants were asked to outline their knowledge of HIV prior to diagnosis and identify the source of their information regarding HIV. Named sources of knowledge and information prior to diagnosis included:

- Leaflets and pamphlets from a variety of sources
- HIV positive people
- Local community education/health prevention campaigns run by the staff of population health, community health or Aboriginal Medical Services
- Community meetings including elders and health providers
- Condoman Aboriginal health promotion/prevention campaign
- Grim Reaper national campaign
- High school education programs
- Needle and syringe program outlets

Seven participants reported that they knew nothing about HIV prior to their diagnosis:

Interviewer: You hadn't seen anything on television about it or nothing in the community?

Carmen: No. Because all that time I been out bush...

Interviewer: So you were living in a remote community?

Carmen: Yeah. That's where I was grown up, out there, out bush.

Seven people reported sketchy knowledge of HIV mainly in relation to health prevention messages regarding transmission of the virus.

Tanya: I only knew a bit of it, like "Safe Sex", that's the only bit I knew.

Six participants reported that they had a reasonable knowledge of HIV prior to diagnosis, with an emphasis on modes of transmission:

Interviewer: Can you tell me what you knew about HIV before you were told that you had it?

Denise: About AIDS. That you catch it by sex or needles and all that.

John: Oh you know, when you go and buy a syringe they tell you. It's clean and you throw it away the proper way and that, you know.

At diagnosis, a number of participants believed the virus was a rapidly progressing fatal disease:

Nick: I didn't even realise the distinction between HIV and AIDS – to me it was the same thing. And you had a year's life expectancy virtually and that was about it.

Bonnie: I didn't really actually know about what it's like. All I just knew about was the germs and it's a very deadly disease. I thought that people could die easy, well, within three years or somethin'.

Jayme: I considered myself as a time bomb, you know.

Ross: Oh. "I'm gonna die." I said, "Oh, no. How could it happen?" You know? I thought I knew the people that I knew that I was messing around with. But I apparently didn't know them very well, what they were doin', you know in their life.

Carole reported little knowledge of HIV. She was still coming to grips with her HIV diagnosis and at that stage, she did not particularly want to be given information.

Carole: I know nothin' 'bout HIV. I know that it can kill me.

Interviewer: What would be a good way of giving you information?

Carole: I don't know. I just wanna wipe it out of my head.

Darren identified as gay. He suspected that he had contracted the virus while living in another state around 1990, although he was not diagnosed until some years later. While he was aware of safe sex messages and reported that he used condoms for casual sexual contacts, he and his regular partner did not.

Darren: They had the Grim Reaper commercials and all that. Like I said, I didn't think I went around and just threw myself around and had sex and no protection and all that. It was just that I was havin', well like I said a person that I thought, you know? Didn't think nothin' of it.

Interviewer: Someone you trusted?

Darren: Mmm, like I trusted the person, yeah. Like I said, where you go with others, you sort of take them precautions but I didn't with the person I knew.

Knowledge in itself was insufficient. Where there was a low perception of risk, individuals continued to engage in high risk behaviours.

Shona was involved in a school and community health promotion project regarding HIV and felt that her prior knowledge was satisfactory. As a teenager she formed a relationship with a man who was HIV positive and despite her knowledge of the virus, modes of transmission and her partner's positive status, after several months of unprotected sex and three HIV tests, she was diagnosed positive also.

Shona: Yeah well I didn't know it was that deadly, or very quick to pass on, I thought it was a slow time disease that might take maybe a year to be...I think we was still havin' unprotected...?

Interviewer: Oh I get you, you knew that you would be at risk but you didn't think you were high risk is that what you mean?

Shona: Yeah.

Interviewer: Did anybody talk to you about the risks and about using condoms and stuff like that?

Shona: Yeah, when they told me then that my partner was.

John stated that a couple of years prior to his diagnosis, there had been a community education meeting arranged by the Health Department and Aboriginal elders in his town and that HIV health promotion and education campaign messages, and information had been widely distributed in the region.

John: Oh yeah, it was all around the place. Yeah, through the AMS medical centre. Through the media, clinics, it's everywhere. I remember a couple of years ago, the old fellas had a meetin' and they was findin' out from the nurse, so they was talkin' to people about it so you'd go there, get tested, so they taught the town I suppose.

(b) Experience of living with HIV

Experience of diagnosis of HIV

The year of diagnosis ranged from 1993 to 2002, with 15 (75%) occurring between 1993 and 1998. Diagnosis occurred in a range of different settings outlined in Table 3:

Table 3: Location of diagnosis

| Location | Number |
|--|---------------|
| Urban Aboriginal Medical Service | 2 |
| Fremantle or Royal Perth Hospitals/Clinics | 5 |
| Urban Prison | 1 |
| Western Australian AIDS Council Clinic | 1 |
| Rural Health Clinics | 11 |
| TOTAL | 20 |

Those participants who had been given post-test counselling reported that they had received it from a variety of sources which included doctors, Aboriginal Health Workers, community health nurses, and social workers.

Darren, who was diagnosed in prison, reported that he was immediately transferred to a segregated unit. He had suspected for some time that he may have contracted the virus and had been tested a couple of years previously but had not collected the results.

Darren: ...part of me already knew and like I said a part of me was, you know, it was a sort of relief that I already knew that was it. So really, yeah...

Interviewer: Confirmed it for you, did it?

Darren: It was more like confirmed.

Interviewer: Did you get any counselling when you got tested?

Darren: Actually, no, I just got it straight in prison. I was straight isolated from everyone else.

Participants described a range of emotions on being informed of their diagnosis, most commonly expressed as feelings of shock or hurt.

Bonnie: Oh well, I got a shock at first. Really it took me by surprise. Yeah, it sorta hurt my feelin's a bit, well the things that was going in my head was very horrible, you know? Didn't think very straight. Yeah, I was so down and couldn't think any more, so it was a bit of a problem there. And it hurt my feelin's in other words.

Olivia: I was shocked. I suppose I don't know if you could explain it this way, but some people say that they think it's like they see your life flash before you.

Another common reaction was "Why me?"

Jay: I tipped the whole surgery up. I said "Why me? Why me?" I wanted to kill myself, but in my mind I had my kids. I ended up makin' the doctor's surgery like a cyclone went through it. I screamed, I done everythin'.

Tanya: I was thinkin', "Why did I have to get it? Why couldn't that person use protection if he had HIV instead of goin' around spreadin' it to every womans?" I was really hurt. Just felt like going off my head...goin' mad.

John had requested an HIV test because he had started a new relationship and his partner wanted to have children.

John: Ah, I was really shattered because I had a new partner, that's when I found out see, 'cause I went for a check up and found out. And my lady, well I fell apart from her because I said I couldn't handle this. Wouldn't want her to handle my pain, so I decided to move back up here.

Yvonne, who was diagnosed at the age of seventeen, reported having no reaction to her diagnosis because at the time she had no knowledge of HIV.

Yvonne: I wasn't upset, because I didn't know much about it.

Interviewer: Did you know what HIV was?

Yvonne: No, I didn't know nothin'. So, I wasn't worried.

Participants were asked to give a reason as to why they were given an HIV test. Their responses are listed below.

Table 4: Reason for HIV Test

| Reason for HIV test | Number |
|---|-----------|
| Contact tracing | 9 |
| Antenatal screening | 3 |
| Routine test/at risk | 2 |
| Alcohol counselling/medical examination | 2 |
| Illness | 1 |
| Other STI diagnosis | 1 |
| Gynaecological examination | 1 |
| Prison admission | 1 |
| TOTAL | 20 |

Darren was the only participant who had suspected that his test result would be positive.

Coping strategies

Participants were asked to identify what helped them cope with their diagnosis when they were first informed and what helps them cope now.

Participants named the following as coping strategies:

- Ignoring it
- Keep doing normal things, getting on with life
- Drinking or other substance use
- Support from partners, family and friends
- Contact with other HIV positive people
- Family counselling
- Support from health professionals
- Religious faith.

Not thinking about HIV, ignoring it and just getting on with life, was a common theme regarding coping with HIV, both as a short and long term strategy. This was not perceived as denial, rather an acceptance of the diagnosis but a refusal to allow it to dominate their lives.

Nick: When I first heard. Probably ignoring the fact helped me cope a lot better. And just getting in to do the volunteer work, I suppose.

John: Oh, you hear about it, you grow up around it and you find out you got it, so you talk about it when it hurts. And you live with it. Then you put it out of the way I suppose. You just keep going, eh?

Several participants described good advice they had received at the time of diagnosis, from “Auntie”, a trusted Aboriginal Health Worker in their community.

Tanya: Like I say, I don’t worry for it. Auntie told me, “The more you worry, the more it affects you. Don’t think about it all the time.” So, I don’t think about it.

Bonnie: I started cryin’, I was upset when Auntie told me that. “Keep calm and you’ll be right and just try to get on with your life and that and do a lot of things without thinkin’ about it.” So, that’s what I did.

Many participants spoke of simply getting on with their lives, doing the normal things that they would have done prior to diagnosis.

Jayme: I just tried not to think about it a lot and just kept doing the normal thing, like going to college, going back to school, work experience. I just didn't really let it pull me down because it's somethin' I can't change and somethin' that's not goin' to get better. So you either have to live with it or just let it pull you down altogether.

Nick: I can, I suppose can put things in their little boxes. The only time I really thought about it was in the mornings when I'd wake up. The first thought would be HIV on my mind straight away. But then I'd push it to the back of my memory, my mind, and just get on with normal work...

Bonnie: Oh, just gettin' on with my life without thinkin' about it because the more you think about it the more it make you mad. Make you want to go off. Gettin' fidgety, don't want to sit still, then you want to go and get drunk and do silly things to yourself and that's the wrong thing, you know? But other than that, I just keep my mind off it. Just do the jobs 'round the house and look after my kids.

Alcohol featured as a common coping strategy, an "escape", particularly when first diagnosed. Many participants later recognised that this was a temporary and ineffective solution.

Carmen: Well at first I thought that drinkin' would help me, but it wouldn't. I had one of my relatives, she was very close to me and she caught on and tried to help me, like talk to me and said, "Oh, you are not the only one," and all this and that. But I did drink a bit too much, but then as she kept on talkin' to me I sort of slowed down a bit.

Interviewer: So did that help you cope then, the drinking?

Darren: [Laughs] It just made it worse.

Jay: I was depressed then like...I'd see like goin' through a bottle. You know, try to drink alcohol to solve my problem and then it puts more headache on me because you think, oh they're out to get you, you know. Like there's the squad comin' out, you know, what you call it?

Interviewer: The DTs?

Jay: Yeah. So you escape to be like in the drug scene, drink, whatever to try to escape, but it still knocks on your door when you wake up next mornin'.

John: Yeah, it shocked me, yeah. I got drunk just thinkin' about it. Drink the shadows away, yeah.

Interviewer: Do you feel getting drunk, does that help you cope?

John: Oh no, just a kind of escape I suppose.

Interviewer: You escape?

John: Yeah, you know. Get the blues, you know?

Some participants used cannabis as a coping strategy to help them relax. John had stopped drinking several months prior to interview, but continued to use cannabis.

Interviewer: Do you still smoke?

John: Yeah.

Interviewer: Bit of gunja?

John: Yeah, I smoke gunja.

Interviewer: Does that help you? What does it do for you?

John: Oh, yeah it helps me a lot, it calms me right down.

Support from partners, friends and family was identified as an important factor in coping with HIV.

Shona: Um, I think it was just helpin' my partner [*also HIV positive*] cope with it too, makin' him think that he is not the only one, he had been in denial. We just pulled through together, we supported one another.

Charlie: Well, havin' my two daughters mainly...helped me to keep strong in myself.

Ross: Oh, where I was stayin' at the time, stayin' at my friend's place, he was good. He was good, him and his missus. They still let me stay there. He didn't let no-one intimidate me, no-one push me around and things. They tried, but he would tell them to go out of his house.

Pauline: My mother...my sister. I talk to them.

Contact with other HIV positive people was named as a coping strategy by five participants.

Jay: I had a cousin who is HIV positive, he sat down with me and he used to say, "Just live day by day. If anybody come up and stare you up and down, just walk off." I looked up to him for support because...when he found out that I was HIV positive. And I had another cousin, he died now, but he used to say, "Oh you look up to the stars, look up to heaven and you know. Live life day by day and live it to the fullest. Don't worry about what people have to say."

Kimberley attended a family camp for HIV positive women with her children soon after diagnosis, which she felt helped them cope better as a family.

Kimberley: It was just like a big shock to him [*teenage son*]. It was like he had to try and put everything together and that, and he realised that he wasn't the only kid around who had a parent who suffered with this, when we went on our first camp together. And then meeting other women that were married or single, who had kids and those who didn't... it did the same things, sorta opened my eyes as well.

Kimberley also named family counselling as a coping strategy for herself and her children.

Kimberley: I'm angry and I don't mean to be angry at them. They have picked it up, they've accepted this, but it's pretty hard. So every time I'm around my kids, since we've had our family counselling sessions, that's helped a lot.

Several participants named being able to talk to health professionals as a coping strategy when feeling down or depressed.

Jayne: Oh, my GP at home. If I need to talk I go talk to her.

Two participants named religious faith as a coping strategy.

Olivia: ...being a Christian, that helps me.

Jay: I remember I used to cry for the first year, every couple of months I used to get a good bawl. My mum used to come in and sit back and she used to pray with me. Pray, pray, pray.

Some participants said that nothing helped them cope.

Carole: How did I cope? I just sat there, feelin' upset, couldn't believe that I had it. It was just a shock to think it would have been me.

Interviewer: What things help you cope now?

Carole: Nothin'.

Interviewer: What things helped you cope when you first knew about it?

Denise: Nothin' really.

Interviewer: What about now, what helps you cope now?

Denise: Just walk around and keep it off my mind. Just get on with my life.

In response to questions about coping, Darren and Bonnie talked about living with HIV for ten years or more.

Darren: Oh, I've got over with that stage long ago. It's just now, I'm just in a different situation now. I think with that thing, I thought I'd be dead a long time ago with my lifestyle. Now I just have to cope with it, because I'm still here.

Bonnie: But the thing when I started gettin' it, the first time I found out, well it's over ten years now and I'm still alive, you know, just copin'.

Disclosure

Ten participants reported that they had disclosed their HIV status to members of their immediate family, members of their extended family and close friends. Two of those had also disclosed to others in the wider community, including tutors, work colleagues or service providers such as hostel staff.

Six participants had informed only a small number of people, which included parents, siblings, children, partners and close friends.

Three participants stated that they had not disclosed their HIV status to anyone.

One participant disclosed to family members because his status had already become known within the prison system and he believed that his family already knew.

The benefits of disclosure included greater social support from family and friends, being able to talk to someone close about their condition and the relief of not having to keep it secret.

Nick: Well, most of my closest friends and family know that I am positive now. So there is no feelin' of having to hide things, so that makes it a lot easier. Yeah. Just being able to tell somebody, I think just get it off your chest was the way to do it, yeah.

Tanya: 'Specially my brothers. They gettin' that close to me now.

Carmen: And I have got a lot more things out of them like, 'specially love from them.

Charlie: A couple of friends said "You right", they still drink out of the same cup. They been really supportive.

Shona: They go quiet then say, "Well, we are not going to chuck you away and make you feel out of place, you just are always just goin' to be the plain old Shona that we knew for that many years."

Participants who had disclosed only to a small number of people restricted their disclosures to those whom they trusted because they did not want others to know.

Pauline: I worry about people findin' out. I only tell people I trust.

Two participants remarked that it was easier to disclose to strangers than to tell family, friends or other members of their community.

Ross: Sometimes it's easier to get on with strangers than it is with people you know. Yeah, because you walk away and you'll never see that stranger again, but you'll see that friend or family again.

Nick: I mean it's easier for me to go and give talks to the wider community than what it is back in my own community.

Three participants, all of whom had been diagnosed for longer than five years, stated that they had not disclosed to anyone.

Frances: I don't talk about it, nothing.

Interviewer: So, you haven't told anybody?

Frances: No.

Interviewer: Have you told any of your family or relations?

Yvonne: No, nobody.

Interviewer: Do you think you might tell your family sometime?

Yvonne: No, I don't talk about that. I don't think about that.

Interviewer: So you haven't actually told anybody yourself or discussed it with any of your family?

Karina: No. It's too hard to tell people.

Karina and Olivia had been infected by their former husbands. Other members of the community knew their former husbands' HIV positive status, therefore their own status had become known or suspected.

Karina: People probably know because they know about my ex.

Olivia: Most of them, being like in the Aboriginal community and a lot of people, like I've got a lot of relatives and sort of you know, people know who you are...like my ex-husband. A lot of people knew who he was, so a lot of people, you know, knew about it.

Negative aspects of disclosure to family or friends included unwanted disclosure to third parties. Five participants reported that a family member, former partner or friend to whom they had disclosed had told others.

Jayne: My cousin actually told some of her friends. And they've asked me and her friends have asked me about it and I've denied it. And I told my cousin, if I want people to know I'll tell 'em myself, I don't need you tellin' them for me.

Ross: My mate's missus, she's told a few people. Such and such told others and it goes on like that. There's no stoppin' it. It's like the virus, you can't stop it once the story gets goin'. It's unbelievable.

Five participants made reference to the difficulty of keeping secrets in the Aboriginal community.

Jay: ...oh, a lot of people know from the Aboriginal grapevine. It's like a one-man newspaper.

Carmen: Like where we live, it's a small community and like everybody knows everybody's business.

Bonnie and Jay were the only participants who reported unwanted disclosure by health providers.

Only one participant said he would have preferred to do things differently regarding disclosure.

Nick: Telling my brothers, well I would like to have been sober when I told them. Because it made me emotional and made them very emotional as well, hearing it on the other end of the phone. And drawing boundaries before I told somebody something, like say, "I've got to tell you something, but don't pass it on," rather than just blurting it out and just leaving it at that, thinking they would keep it confidential and you know, be confidential.

Discrimination

Discrimination mainly consisted of being treated differently by friends and family in relation to sharing cups, dishes or drinks or others keeping their distance from participants for fear of catching HIV. Five participants reported instances of this type of discrimination.

Seven participants reported that they had not experienced any discrimination by family, friends or community members in relation to their HIV status.

Eight participants reported that they had been insulted or called names such as an "A.C.C.", or had graffiti written about them in relation to their HIV status.

Jay: I was being called a, "You are a A.C.C." That means a AIDS carrying c-u-n-t, from females and males, your own family, like your cousin, your uncle...you can't even touch your own niece, little baby or anything. Can't even nurse, "Oh no, you'll get AIDS." They think that you can't share from my drink or anythin', because you'll get that.

Shona: Yeah, because like if we had a fight and like, one of you ended up being split. Or some of my friends or other people don't like using the same dishes and try not to have a drink out of that or...they watch me and things like that. Tell others to keep away and I tell them, you can only get it if you got an open cut too.

Ross: ...well there's one woman in particular, she was screamin' out from one side of the road to the other. "Go away you HIV bastard," and all this, you know. "You've got AIDS." And she'd have this biggest mob of people around her. Oh, it does, it makes you feel that small. I walk away from that. But every time you bump into them it's on again, you know, you gotta be careful which corner you walk.

"Slinging off" at individuals regarding HIV/AIDS is sometimes used as a general insult, particularly among those who are aware that HIV exists in their community, but who don't know the identity of those affected.

Interviewer: Has anybody told others that you are positive without getting your permission?

Pauline: No, but people been slingin' off at me, sayin' I got it.

Interviewer: How do they know?

Pauline: They guessin'.

Tanya: One girl was callin' me a A.C.C. They was fightin', her and another girl. My name got mentioned an' she called me a A.C.C. I said, "Why you fellas put my name into your argument for?"

Interviewer: How does she know about you?

Tanya: She guessin'.

Carmen: A couple of ladies slung off at me, and that sort of made me like I wasn't the same as them, like it did hurt me. And all I could say was, "Oh, how do youse know?"

Darren reported that his status became known, particularly within the Aboriginal community, due to his transfer and segregation in a special unit within the prison system, which identified him as HIV positive.

Darren: ...everyone already knew. And being like I said, being an Aboriginal and in jail. They just already knew...and being Aboriginal, even if you're not related to them, you know someone who does.

Darren's name and his HIV status was published in the newspapers as a result of legal action he had pursued regarding discrimination.

Darren: I couldn't understand how they could do that. If they were allowed to. Put my name, my full name and everything and what was wrong with me so it was something, well, like I said, I think people already knew. That there just opened the doors wide open, so I just didn't care.

Interviewer: What sort of effect did that have on you, that you know, printing your name like that?

Darren: I was pretty angry, you know. Like I said, more than...not the shame, just the anger of it.

All participants were asked if they had experienced any discrimination by health service providers because of their HIV status. Eighteen said they had not experienced any discrimination from this source.

Jay: No, no. It's like caring and everythin' like that.

Karina: No. They be nice.

Only two participants, Nick and Darren, reported that they had experienced discrimination from health providers due to their HIV status. Nick and Darren were the only two of the twenty research participants who identified as gay. It is possible that the discrimination they experienced was based on homophobia in addition to their HIV status.

Nick reported that he had experienced discrimination at the Dental Hospital.

Nick: ...they tell you to be up front, always put down positive on the form, and then once you do you realise it wasn't a good idea...had two big fillings put in because my old fillings had fallen out. Each time I've gone back they've said, "Oh no they're still okay, come back in six months." So I keep getting put back on the back burner. So I go in the dental chair, lay down, they go and look at the X-rays, look at the form, they say, "Oh no, we'll just have a quick look in the mouth," and say, "No, come back later." So now another dentist will get the problem later on sort of thing. So I've never gone back.

Darren had experienced discrimination from nurses in hospital and in prison in the early nineties, gowning and gloving to perform minor tasks such as taking his temperature, which made him feel stigmatised and angry at the time.

In the early years of the HIV epidemic it was the policy of the Department of Justice in Western Australia to transfer prisoners who were HIV positive to the prison infirmary in a maximum-security urban prison, segregated from other prisoners. This had several negative effects. Due to the segregation, their HIV status became known to prison officers and to other prisoners, causing distress and stigmatisation. In addition, prisoners who were HIV positive were not allowed to participate in educational, recreational or other programs which were available to the general prison population. Two prisoners took their complaints to the Human Rights and Equal Opportunity Commission. In December 1996 the Commission found that prison policies were discriminatory and ordered compensation to be paid to the complainants (AFAO 1996). As a result, prisoners who are HIV positive are no longer segregated.

Darren's experiences of prison health services stemmed from several years ago, when the segregation policies were in place. He experienced isolation, distress and stigmatisation as a result.

Darren: ...there was some good ones, you know what I mean? They were fine, but most of them would chuck gloves on and all that, gear themselves up. There were a few like I said, who are well aware that it's fine, and you don't contract it like that or nothing. Then you've got them other ones.

Despite many participants reporting that they had not experienced discrimination, they were clearly aware of the potential for it to occur. The reluctance of some participants to disclose their HIV status to significant others in their lives appears to be linked to worry that discrimination may result from disclosure.

Social support

All twenty research participants named close family members and/or partners as their main source of social support.

Interviewer: In thinking over the whole experience of living with HIV, what has been the most important change or the biggest change that has taken place in your life?

Charlie: My families are closer. My daughters are...well the eldest one is really close.

The need for social support motivated three participants who had lived on the streets and consumed alcohol to excess prior to diagnosis to return home to live with their mothers and siblings, two of them moving from the city to rural towns to do so.

Nine participants named various health providers as additional sources of social support.

John: So I got a lot of help from AMS. I've got a lot of help from there because they're Aboriginal. I'm still getting a lot of help from the doctors and nurses, the health workers and this health mob here now, helping me out.

Nine participants named other people who were HIV positive as sources of social support.

Nick: Just being able to bounce things off people, talking about medications or treatments. If they're not feeling well...and being able to tell somebody "I'm not feeling well," and they know why and they can understand. Even the simplest, silly little things, like just saying, "Oh, I'm just tired." Knowing that when you say you're tired, you're really, really, totally exhausted and not just being flippant sort of thing, like other people might think.

Carmen had been given support by a relative who was HIV positive soon after diagnosis. She had also met other Aboriginal women at retreats and found it helpful to talk to them. In turn, she had offered support to others in her community.

Carmen: Well, I tell people, because they think I don't know about them and I am just sort of tellin' them. Like there is a girl I know, I tried to get her to tell me about herself but she won't be in it.

Interviewer: So do you know she's positive, or do you just think she's positive?

Carmen: Yeah. She is positive...but she sits down and she thinks that nobody knows about her and she does get very sick now and again. She is very close to me, she is a relative of mine.

Interviewer: So you would like to give her a bit of support?

Carmen: Yeah.

Ten female participants had attended Positive Aboriginal Women's Retreats arranged by the rural health service in the regional area of special need. Six of these reported that they maintained contact with other women from their communities with whom they had attended retreats. The remaining four did not, because the women they had met lived in other parts of the state and communication between them was too difficult.

Two participants, Nick and Kimberley, had attended retreats arranged by the Western Australian AIDS Council, where participants are generally non-Aboriginal. Nick had met other Aboriginal men who are HIV positive when attending conferences interstate, but he had not met any locally.

Only two of the remaining eight participants, John and Olivia, had no knowledge that retreats were available. Three had been invited to attend retreats, but had declined because they were worried that they might meet Aboriginal people who knew them. Ross was considering attending a men's retreat and Carole was booked to go on a future women's retreat. Darren stated that he would attend an Aboriginal men's retreat if he had the opportunity.

Jayme: They tried to get me out to one of those, but oh, I don't know if I want to go. I mean I'm all for it when they come around, but when it comes to time I actually get cold feet and want to back out. (Laughs).

Interviewer: What are you afraid of, do you think?

Jayme: I'm afraid to go to things like that and find that somebody else I know has actually...and you know I'll probably stand there and just probably think to myself, well, why didn't she bloody tell me, you know.

Interviewer: So, would you be worried about meeting other people that you know, who are positive?

Jayme: Yeah.

Interviewer: What about people you didn't know? Maybe people in Perth or from the country?

Jayme: Yeah.

Interviewer: Would you go on a retreat if they were strangers?

Jayme: Yeah.

Interviewer: Would it make any difference if they were Aboriginal or if it was a mixed group?

Jayme: Oh, I actually...oh well, because I'm a multicultural person I actually would like to have not just Aboriginal or you know...I like to be mixed.

Retreats provided an opportunity for participants to meet other people who were HIV positive, to obtain information regarding HIV/AIDS and the services available, and to participate in recreational/leisure activities away from their own communities.

Tanya: (Smiles). It was good all right...we hired a bus at the airport, stayed at a hotel...shoppin'...drivin' around. We did painting, got a haircut when we was comin' back. Went for a ride, went out places...Kings Park.

Jay: It was good for me...I finally met other women who were HIV and we got along all right, you know, how we feel. We cried and we had cups of coffee and you know...like we was old people, people havin' a gasbag...and it gets you a load off your chest or somethin', you know.

Jay had previously been friendly with a non-Aboriginal woman who was HIV positive:

Jay: ...she was more straightforward, more than an Aboriginal person. But then you got an Aboriginal person they have so much hatred in them. It's like, you know, you want to kill that fellow, the one who gave you that, you know. Then in a way, the white girl, she just says, "Oh look, it was a bad choice."

Carmen had attended a conference as well as a retreat.

Carmen: I found it a bit interestin', like there was a very lot of people, mans and womans...they wanted us to talk, they mentioned our name but I got a bit shy. A lot of people got up and showed their feelin's, cried and sort of made us feel you know.

Interviewer: So was that good for you?

Carmen: Yeah.

Pauline mentioned that when small groups from her community left together to attend a retreat, others in the community gossiped and the potential existed for their HIV status to be identified. She suggested it was better to have people from different parts of the state attend.

Pauline: I want to go on retreat and not let everybody know what I'm doin', where I'm goin'. Because if girls get together everybody in town knows. I wanna meet other people with this condition that don't come from here. People that don't know me.

Six participants stated that they would prefer to attend "mixed" retreats, where women from different cultures attended. Kimberley stated that she would not attend an Aboriginal retreat.

Kimberley: ...I've only ever met one Aboriginal that's got HIV.

Interviewer: Okay. Would you like to? I mean if there was an Aboriginal retreat?

Kimberley: No, not really. Which is, it's a close knit community, and it would get back to my family before I'd even told them and I wouldn't ever go that far – at all.

Ross stated that he would prefer to meet Aboriginal men and women from his own “mob” or linguistic group, who are HIV positive.

Ross: I just want to meet some more people with HIV. I want to learn about that, different things and what's going on so I can work out for myself. That would be the best way to work things out, to talk to somebody else in your boat...it's easy to talk to your own people.

Economic impact of living with HIV

Living with HIV did not appear to have much economic impact on the participants. All twenty participants were on very limited incomes, yet apart from two people who had given up employment, the majority did not believe that HIV had adversely affected their financial situation or their accommodation. Low incomes are the norm for many Aboriginal people.

Income

Only one of the twenty participants was employed. He was employed under the Community Development Employment Projects (CDEP) scheme and his income was similar to unemployment benefits. Participants' sources of income are outlined in Table 5.

Table 5: Sources of income

| Sources of income | M | F |
|-----------------------------|----------|----------|
| Disability allowance | 2 | 7 |
| CDEP | 1 | 0 |
| Abstudy | 1 | 0 |
| Unemployment benefits | 0 | 3 |
| Partner employed | 0 | 1 |
| Supporting Parent's Benefit | 0 | 5 |

Eight participants stated that they had enough income to meet basic needs.

Charlie: I'm on disability support pension. I have enough for this and that, personal stuff and things.

Interviewer: So do you feel that you have enough for everyday living and food?

Charlie: Yeah.

Interviewer: Yeah? Has having HIV made any difference to your financial situation?

Charlie: No, I don't think so.

Frances: I got pension money. It goin' in the bank for me...I got enough money...I got enough money for sugar, tea bag an' all. Flour for damper.

Interviewer: What about meat?

Frances: Kangaroo. The boys go out shootin' an' bring me back. I pay for petrol.

Twelve participants stated that they did not have sufficient income to meet basic needs.

Darren: ...but with the pension, and you try and eat well and all the rest of it you know, sometimes it's a struggle...it's hard to make sure you've got food and everythin'. Sometimes a bill comes.

Shona's partner was employed, but earning a minimum wage. They and their children lived with relatives.

Interviewer: Do you have enough money for food and everyday living?

Shona: No, not really...when the electricity bill comes in we go halves, or sometimes we can't pay it because we have to buy food. Like the meat, because he takes his gun, you know?

Interviewer: Oh yeah, getting roo you mean?

Shona: Yeah, kangaroo meat and all that.

Eighteen participants reported that living with HIV had not made any difference to their income.

Interviewer: Can you tell me how you manage financially, if you have enough money for food and everyday living?

Tanya: No, I don't have enough.

Interviewer: What would be different about your financial situation if you didn't have HIV?

Tanya: No difference. Been like that already.

Olivia and Nick reported that their incomes had dropped because they had had to stop working due to their HIV diagnosis or to the side-effects of medication.

Olivia: Well, I had been working before then, but just recently I sort of stopped working. I only had part-time work but...like if I was still working I'd probably have enough, but because I'm on the pension it does get a bit hard.

Nick: It was a bit unsettling in having dizzy spells. This limited me in the sort of labouring work that I was doing. I suppose now, any little physical work I've got to keep in mind that some days I just get too tired, just worn out, can't do it.

John worried that he would lose his employment with CDEP if anyone found out about his HIV status.

John: I don't know whether to tell them I got it. I don't really want them to know. I don't know if they should know about my health or whatever. But if someone's got to tell them, I don't know if I'd lose the job or not.

Interviewer: Do you think you need to tell them?

John: I don't know. That's what's the most frightening thing. I'm scared I'll lose the job.

Accommodation

At the time of interview, participants' housing situation was as follows:

Table 6: Accommodation Type

| Accommodation Type | Male | Female |
|---|-------------|---------------|
| Homeswest* or Aboriginal Corporation Housing tenant | 1 | 5** |
| Living with relatives | 2 | 9 |
| Hostel | 0 | 2 |
| Sharing private rental accommodation with friends | 1 | 0 |

**Homeswest is the division of the Department of Housing and Works which provides low cost housing to eligible tenants in Western Australia.*

***Although one participant was in prison, Homeswest accommodation had been arranged for her on release.*

John and Carole reported that they had moved from the city to live with parents in country towns soon after diagnosis. Ross had also moved back to his mother's home, although he remained in the metropolitan area. All three reported that they had been living on the streets and drinking alcohol to excess prior to diagnosis.

Ross and Jay were awaiting Homeswest accommodation and both were on the priority housing list.

Charlie had previously rented Homeswest accommodation, but had relocated after a relationship breakdown and was temporarily living in a hostel.

Social impact of living with HIV

Research participants were asked to describe how their HIV diagnosis had changed their lifestyle, the way they socialised or met new partners. They were also asked if HIV had changed the way they thought about the future.

JOHN

John had been living with HIV for a year and his lifestyle had actually improved in many ways. Prior to diagnosis he was in and out of prison, living on the streets, binge drinking and not eating properly. The initial motivation for John to change his lifestyle was not his HIV diagnosis, however. This was due to forming a new relationship. He had decided to seek alcohol counselling and change his lifestyle with a view to settling down with his new partner. He was given a health check, including HIV testing. The HIV diagnosis ended his new relationship.

John: I had been on the streets for about six to four months. Yeah, I got off the alcohol. 'Cause I had been binge drinkin'. I know all the mob on the streets. Got out of that, off the streets and then started workin' on it, alcohol counselling. Then that...it ruined my relationship. Finished with me when she found out.

After another period of binge drinking and being charged with a petty offence, John was placed on a Court Order with a special condition forbidding him to consume alcohol. He was also required to perform community work. At that point, John ceased drinking and made an effort to improve his health. He gained a reputation as a good, reliable worker through attending his community work, then started working at the local Community Development Employment Projects (CDEP) scheme.

John: When I went to court and that, I wasn't allowed to drink alcohol for six months, and that cleared all the alcohol in my system and that...Like I say, which planet I've been on? Which planet you on, you know. (Laughs).

Interviewer: Have you been to prison since you were diagnosed?

John: No, no. No, I reckon when I came out...when I came out of prison, that's when I found out. And I don't know who or where, or why.

John remained single and didn't socialise with friends as much as he did previously.

Interviewer: What about meeting a new partner? Do you still manage to meet a new partner?

John: Ah yeah, sometimes.

Interviewer: Is it difficult or is it okay?

John: No, it's difficult I suppose. I get turned off by the idea.

John's goals were to be independent, and to obtain a disability pension and Homeswest accommodation of his own. He was aware that he was eligible for both, but he was reluctant to disclose his HIV status to local Homeswest or Centrelink staff in his application.

Interviewer: Is it hard living with the family?

John: Yeah, very hard. It's been hard for a year. Tryin' to shrug it off, but sometimes I have a bad day, right...I've been tryin' to get a flat up here...I want to get out of that place, yeah. I want to stay in this town, but I can't get a flat. It bothers me, 'cause if you're able to get a flat, see, then you can do your own thing...I'd like just to have a flat, my own little pozzie here.

John indicated that the biggest change in his life in living with HIV was in not knowing what the future might bring and in trying to keep a positive attitude.

John: I find it hard because sometimes you want to do things that you sort of can't do. Find it hard to do things. Don't know what tomorrow gonna bring, so...Yeah, sometimes I think about it and I'll have a few things come into my head and I'll think about it. It's hard for it to come out in a positive way. That's all I say, not a negative way. I'm thinkin' in a positive way...It's gonna just get worse, so that's all I gotta say, just thinkin' in a positive way I suppose...I'm tryin' to turn my life in a different direction, that's how I'm comin' at it, all the time.

SHONA

Shona was a young mother, who had been living with HIV for around five years. She liked to keep busy with her partner, children and extended family. She tried to maintain normal activities and not let her HIV diagnosis impact too much on her lifestyle. She played sport and socialised with friends and family. She worried about the effect on her children if she or her partner died of HIV/AIDS.

Shona: ...like when they get big, 'cause we could die anytime, unexpected and they haven't got...(pause) What we died of and how, and all that sorta thing. I sorta think about that.

Shona maintained contact with other women in her community who were HIV positive and offered them friendship and support. She was enthusiastic about the current research study.

Shona: Can I just say I am very proud of myself for doin' this interview with you and hopefully down the track there will be more to come.

Shona was asked how HIV had changed the way she thought about the future.

Shona: I haven't changed a lot. No, I'm just lookin' forward to bringin' my kids up now, yeah.

OLIVIA

Olivia had been living with HIV for around five years.

Interviewer: In thinking over the whole experience, you know, of having HIV, what's the most important change in your life, that's taken place because of it?

Olivia: ...The importance of life. Yeah. Yeah, like you want to look after yourself a bit more and that.

Interviewer: Is your life a lot different from what it was then?

Olivia: Yeah. I'd say yes.

Interviewer: What kind of ways is it different?

Olivia: ...you sort of live like from day to day. That's sort of how you know I started off from day to day. Accepting each day as it comes.

Olivia was a quiet, shy person who spent most of her time with close relatives. She had given up her part-time job and had stopped going out socially. She was single and felt that HIV prevented her from entering a new relationship, although she would have liked to have a partner. Her Christian views meant she was not interested in sexual relationships.

Olivia was being treated for depression and had no contact with other Aboriginal people who were HIV positive. Her life was focused around her family and her faith. She seemed to be the most isolated of the twenty participants and her knowledge of services for people who are HIV positive was limited.

Olivia was asked how HIV had changed the way she thought about the future.

Olivia: It's like with being a Christian, the future is like forever, you know. Like with another part of me, I think about dying a lot. Like it's there, and you can't you know, get it out. But yeah, like with being a Christian, sort of positive future.

JAY

Jay had been living with HIV for approximately two years. Her HIV status was widely known in her community, which caused her feelings of shame and stigma.

Jay: ...it brings up one stigma that "Oh look here, don't go sittin' with her because oh, she's HIV pos." Oh and the next minute, "Oh, she's got AIDS"... "Don't go with her" or, yeah, "Don't let her in your house. Oh, don't let her in your car"... Like you can't even shake a hand. I said, "Oh, shake a hand or kiss on the cheek." "Oh, no don't." ...or even a hug. You can't get HIV from doing that.

Jay found it difficult to form new relationships.

Jay: ...“Don’t go with her because you know, you got a death warrant.” Death warrant. That’s like the local slang.

She spoke of the barriers that her HIV status caused when she did meet a potential partner.

Jay: It’s very hard. Like if there’s a boy that comes up and he starts talkin’ and he’s got that gleam in his eye and you can feel it. He can feel it. It’s like, I don’t know, how you say, the door of heaven opens (laughter)...You think, “Where was he before you knew that you was HIV positive?” That is a barrier, because it’s too hard to tell them, you know. Then you end up puttin’ another excuse there so he can put a condom on and say, oh, that you don’t want any more kids and you’ve had enough...But then you got other people, other boys that you know, they know that you’re HIV positive and they willin’ to put a condom on just to have some good sex.

Jay spoke of one man she had been with, who had subsequently found out about her HIV status.

Jay: ...I used protection with him. He’s got me a bit paranoid because he went round tellin’ everybody and everybody’s talkin’ ’bout me. Oh, he’s out for to kill...I don’t know if he’s goin’ to come walkin’ along here with a gun or a knife or you know, cut my guts out or everythin’ like that.

Jay reported that re-establishing the relationship with her children was her main priority and was the biggest change in her life since diagnosis.

Jay: The change is that I’m livin’ for another life for my kids. My children are growin’ up and I want to see them grow up and graduate, get married if I live that long. But I just want to be with them every time. I’m startin’ to realise because I wasn’t there when I only just gave birth and I was too busy runnin’ off and willy-willy goin’ round.

Jay was at the stage where, although she still became depressed at times, she was beginning to accept her condition.

Jay: I just learn every day just to live with it.

Jay’s comments on thinking of the future were:

Jay: Always have a prayer when I go to sleep. I’ll say, “Oh, God forgive me for whatever I done, but I love you and everythin’, look after my kids. Look after me,” and that’s it. “Amen.”

DARREN

Darren had been living with HIV for more than ten years at the time of interview, years of wondering what tomorrow would bring. He had not expected to live so long.

Interviewer: Has it made big changes in your life, do you think?

Darren: In the way I think. Yeah, the way I think. At one stage, where you just don't know what to do most of the time.

He had been a binge drinker, but in recent years he had changed his lifestyle and appeared to have some regrets that he had let the years slip away.

Darren: Life in general, yeah, I wasted so much, I just sat dwelling on it.

Darren had cut down his alcohol consumption and was in the process of regaining his driver's license and saving for a car. He had moved into his own Homeswest unit with a relative several months previously and was still settling in. He was interested in becoming a positive speaker. He reported that he would have liked to have done this some years previously.

Darren: I could contribute by going out speakin', but like I said, no-one was interested, so I just don't care any more...Oh yeah. I was really serious about it at one time. No-one wouldn't employ me, anyway. They have people who don't even have a disease. I've had so much experience and thoughts and I thought it was a good idea to share all that.

Darren had reached a stage where he appeared to want to do something different with his life.

Darren: I want to go and do somethin', but I can't, I'm just too tired.

Darren identified as gay. He did not believe that HIV had affected his social life too much.

Interviewer: What about socialising, meeting a new partner? Has your condition had any effect on that?

Darren: Not really, no.

CHARLIE

Charlie had been living with HIV for around nine years. She had ceased drinking for six years and she felt that she had “slowed down” and kept to herself more because of her HIV status. She socialised only with family and close friends. She had female relatives who were also HIV positive.

Interviewer: Can you tell me how HIV has changed the way you enjoy yourself?

Charlie: Sometimes it does, when you go out. Soon as you go home to the family it’s better. That’s more fun.

Charlie had been in a relationship for several years.

Charlie: It was awkward at first, but then it changes. He sorta accepted it.

Charlie and her partner had separated, however she thought they would probably get back together again. She reported that living with HIV made it difficult to start a new relationship.

Charlie no longer let HIV dominate her life.

Charlie: I was shocked at first, when I was told. Now I’m used to it.

Interviewer: So, it’s not as shocking now?

Charlie: No, now I can accept it.

YVONNE

Yvonne had been living with HIV for nine years, since she was a teenager. She appeared content with her small circle of friends and relatives. Yvonne stated that she had never been a drinker, either before or after diagnosis. She tended to ignore her HIV infection and she did not believe that it had made much of an impact on her lifestyle. She had not disclosed to anyone. She was single, had one child and enjoyed being a mother, but had no plans to look for a partner or have any more children.

Interviewer: Is it hard to meet a new man or start a relationship with a new man?

Yvonne: No, I’m happy on my own. I don’t want no other man.

NICK

Nick had been living with HIV for around eight years. The fatigue and tiredness that Nick suffered due to his HIV infection had a negative social impact, in that he had given up work, although he was still involved in tertiary studies. It was often an effort for Nick to complete assignments in time. He also did not have the stamina to party on with his friends, the way he used to.

Nick: Yeah, I suppose not being able to keep up with family and friends and that, when they go out drinking and smoking or just partying. Yeah, sort of like after about three hours I go, "I've got to go home now, see you later." You get tired and just get over it.

Living with HIV created some barriers in looking for potential new partners, with the result that Nick spent more time just having fun with friends than he would have prior to HIV diagnosis. When he did meet a new partner, HIV had a negative effect.

Nick: Yeah, I always go for the safe sex line now, especially when sometimes they say they don't want to. Even before we go there, even with safe sex, I state straight...Virtually before we get too heavily into action or whatever, that I am positive, HIV positive. Like I suppose kissing and stuff like that, once the clothes start coming off, I say "Hang on, we got to talk about this." Outline what the go is and why.

Interviewer: So, does that have a negative impact on meeting new partners or...?

Nick: I suppose if you think there's going to be a rejection, you don't go there in the first place. Then when you do it's like, okay well it's your loss, whatever, you know you just walk out. Or sometimes after you've had your sexual encounter, the next morning or just after, things can get a bit hazy with feelings and that and sometimes it's like either one of us could have been too...you know, just can't wait to get out of the room sort of thing.

Interviewer: Oh right, okay.

Nick: You know, get caught up in the passion, then once the passion's over then their mind starts clicking over.

When asked what had been the most important change in his life in living with HIV, this was Nick's response:

Nick: I suppose the realisation that nothing lasts long in its present state or whatever. Whatever your living standards or life expectancy or whatever, and realising that there's a...like don't take things for granted and I suppose you take whatever you get and sort of embrace it, sort of thing.

Prior to diagnosis, Nick was more carefree.

Nick: Pretty happy go lucky I suppose, I didn't have any real cares. At the same time didn't have any real focus on where I was going or what I was doing. Just working...and taking day by day virtually.

Nick described himself as being "more focused" and having more of a purpose for things he wanted to do, since diagnosis. In thinking of the future, he said:

Nick: Need to get as much done as possible in the shortest amount of time. Not thinking you know I'm going to be terminating or anything like that too soon in the future. But it's a case of if it needs to be done and let's just go and get it done.

TANYA

Tanya had been living with HIV for six years, since she was a teenager and she indicated that HIV had had a negative social impact on her lifestyle. She reported that she had stopped drinking and smoking cannabis, and that she had slowed down and "stopped doin' things" to safeguard her health. She described herself as "miserable" and no longer a "happy-go-lucky person".

Tanya was also unhappy with her relationship and expressed a wish to "be single again". She had one child and was expecting another. Tanya did not believe that her HIV diagnosis had negatively impacted on forming a relationship with her partner.

Tanya: My de facto, he didn't know at first. It was so easy. When we was goin' strong, I told him. He said, "Don't worry 'bout it. I been seein' another girl, she got it too."

Interviewer: Did you use condoms?

Tanya: At the beginning, we used condoms, then he said don't worry 'bout it.

When asked to describe how HIV had changed the way she thought about the future, Tanya replied:

Tanya: No difference. I don't worry for it.

ROSS

Ross had been living with HIV for less than a year and he was still getting used to his diagnosis. His lifestyle had actually changed for the better because he had been living on the streets previously leading the life of an “alcoholic”. His income and accommodation were more stable and apart from boils, his health was satisfactory. He had experienced some discrimination and name calling and his HIV status was well known in his community. Another area in which his HIV diagnosis had had a negative impact was in not being able to participate in sport, in case he put someone else at risk.

Ross: I wanted to get out and play a bit of sport and that, but I can't...I might get knocked unconscious you know, on a football oval. A lot of those get carried off bleedin'. If you're unconscious you can't tell them nothin'.

He was at the stage where he would have liked to look for employment, however he had similar fears regarding work.

Ross: I've worked all my life but now, after this here since I've been diagnosed with HIV I've been turned off work. Yeah. Miss the money, but I don't want to start a job and have an accident and tell my co-workers to go away because I've got HIV. So I'd rather not just be there...yeah, I don't want to explain to anyone. Have to say, “Go away, don't touch me,” if I was bleedin'.

Ross's relationship with his girlfriend had broken up soon after diagnosis. He had not yet thought about meeting a new partner, but when asked about this, he felt that it might be difficult.

Ross: Oh it's hard. I can't see it happening now...You can't go up to a girl and say, “I've got HIV, you know, want to go out with me?” (Laughs). No.

Interviewer: So it's a big barrier for you?

Ross: Yeah, it's a big barrier for me now. Oh that's for sure. Unless she's HIV positive as well, so until that happens or if it ever happens I don't know. If I met a girl that's HIV I would get to know her, yeah.

When asked how HIV had changed the way he thought about the future, Ross replied:

Ross: I've gotta be a bit more careful about things. You know it's there, something there that can easily be caught, just grab you like it does. You just got to be careful. Watch what you're doin' for the sake of others.

JAYME

Jayne had been living with HIV for nine years at the time of interview. She had been in a relationship for several years and had one child. Her partner refused to use condoms and she worried about him becoming infected.

Jayne: ...He just cracks the shits...he tells me, "You want me to wear a condom? Are you seein' someone else behind my back?" And I say, "No, no."

Jayne's partner did not wish to discuss the possibility of contracting HIV, nor did he wish to be tested.

Jayne: ...he doesn't want me talkin' about safe sex or HIV and he gets really aggro. Just doesn't wanna talk about it or you know.

Interviewer: Does he get tested now and again?

Jayne: No, he takes off every time the clinic nurse comes around...And they know who he is, but if he doesn't want to have the tests done, that's his choice. I tell him you know, "Hey, I'm concerned about you." He says, "Don't worry 'bout me." But he says, "I choose not to have the test done." So I said, "Well, if you don't have the test done and you're havin' relationships outside of our relationship you're actually puttin' other people at risk." But he just refuses to. And I've actually been spoken to by the Health Department because I told him that I wanted to use protection. I got into a lot of trouble with the Health Department because I told them that he refuses to use protection. Yeah.

Jayne reported that she was careful regarding any blood loss so that she did not put anyone else at risk.

Jayne: Just got to be careful around...like if I'm bleedin' or anything I have to be careful.

Jayne had longstanding, unrelated health problems, but despite this she refused to let her HIV diagnosis dominate her lifestyle.

Jayne: I still do the same things I used to do but I'm a bit...I'm very careful about the company I'm in. I try not to go overboard, stuff like that.

Interviewer: How do you mean?

Jayne: Um, like don't have too much to drink just in case...I don't smoke, I don't do drugs, but I do like the occasional drink.

Jayme believed in being optimistic and making a conscious effort to think positively.

Jayme: I mean I wake up every mornin' ever since I found out I was positive, wake up every mornin' thinkin' okay, I got this day, I'm lookin' forward to it, see what it brings for me.

When asked how HIV had changed the way she thought about the future, Jayme's response was:

Jayme: It hasn't changed a lot of things for me. I mean, I just look at everything the same as I used to before I found out. Well my thing is, I plan to do this and that, but now I have this illness it just makes me more determined to get up and do things, but minus a few things.

Jayme's final comment at the conclusion of the interview was:

Jayme: Well all I can say is I hope they hurry up and find a cure. (Laughs).

KARINA

Karina had been living with HIV for seven years after being infected by her former husband, who then left her for another woman. Although she had not disclosed to anyone, others in her community guessed her status because her ex-husband's status was known or suspected. She stated that he had infected other women in the community, including relatives of Karina's, which had caused her shame and embarrassment. As a result, she kept to herself and tended to socialise only with close friends and family. She and her children lived with family members.

Interviewer: How has HIV changed the way you socialise or meet new partners?

Karina: It's hard to meet mens. HIV makes it hard.

Interviewer: In what way?

Karina: Because you have to tell them and I like to keep it to my own self.

Interviewer: Is it hard to get a man to use a condom?

Karina: Yeah.

Interviewer: Would you like to meet a new man?

Karina: No. I'm not worried about mens.

Karina tried not to let HIV impact on her day-to-day life too much.

Karina: I just be normal. I don't let HIV make a difference.

When asked how HIV had changed the way she thought about the future, Karina's response was:

Karina: I don't think too much about it.

CARMEN

Living with HIV for eight years had made many changes to Carmen's life. She had been without a partner for several years, but had formed a new relationship a few months prior to interview.

Carmen: Like for all HIV womans and mans, like if you are in a relationship you have to tell that person.

Interviewer: Does that make it hard?

Carmen: Yeah it does make it hard and it does make it hard for you to even socialise with other mans. Like I said, in a community what we have got, a lot of people they can say "Oh look who she's with"...And you could just be sittin' down and drinkin' with them and they will say, "Oh look who she's with," and all this and that you know.

Interviewer: What about trying to negotiate safe sex? I mean if you met somebody that you liked and you were going to be with them for the night, is it hard for you to try and get them to use condoms?

Carmen: Oh in a way because they, or some mans, they say, "Oh why you usin' condoms for?" you know, like that. Like just make it fun and I say, "Oh you don't know what you might get these days eh?" just sort of go along with them.

Interviewer: Does that usually work or is it hard to get them to use it?

Carmen: Well, to me it is hard.

Carmen had restricted her socialising to close friends and family. She also had ongoing contact with other HIV positive women in her community to whom she offered friendship and support.

Carmen: Well HIV did change me. I still have my drink but not as heavy as I used to. Like I still get that feelin' that a lot of people still talk about ya...Yeah, I used to socialise, I would go out a lot, not with a lot of boys, but I still mixed in with a lot of boys and girls, go drinkin', go disco, go pub and things.

Interviewer: So you don't do that now?

Carmen: No I just like to sit around with my friends and drink, like my families especially, like the very closest friends that is part of my family, because they grew up with my families.

Carmen had spoken of feelings of shame when she was first diagnosed.

Interviewer: You said before at first you felt shame, so do you think that is less now?

Carmen: Oh a little bit, but not as very shame as it used to be...Yeah. Before I used to cry and cry, but now I am startin' to live with it now and accept that, what I got.

Carmen felt that HIV was a punishment for having sex with someone with whom she should not have had a sexual relationship.

Carmen: Yeah, um well...that fella, we grew up in the one house see, and to me what I always think is that...like that was a punishment for me, like I did deserve it...and in another way I didn't.

Interviewer: How do you mean a punishment?

Carmen: Yeah, well we all grew up together and like we should have respected one another.

Interviewer: You mean you shouldn't have had sex with that boy, is that what you mean?

Carmen: Mmm.

Interviewer: Okay, so you feel you kind of broke the rules a little bit?

Carmen: Yeah. Like whenever we see one another we still sit down and talk about it and say we shouldn't have done it, but it's already happened.

Interviewer: That's right. You can't change it now.

Carmen: But I told him he should have told me because I wouldn't be like this here today. So, in a way I blame him but sort of we had a talk and it's in the past now...We just get on with our lives. We try and help one another now.

Carmen had weathered depression, shame, fear of dying, and the inability to have more children due to a hasty tubal ligation when first diagnosed. She had made many adjustments in her life, had learned to live with HIV and was happy to have a new partner who accepted her HIV status.

KIMBERLEY

Kimberley struggled with drug addiction and had pre-existing health problems to deal with. She was still getting used to living with HIV, having received her diagnosis only one year before.

Kimberley: I still think I'm in that shocked space.

Interviewer: But, sounds like you are getting yourself back into everyday life too?

Kimberley: Yeah, I have to. I have to get myself into workin' how I was before this all happened. Because it took me a long time before this happened to get back on my feet and get into a routine, you know what I mean?

Kimberley had been infected when she had a casual encounter with an ex-boyfriend. As a result, the de facto relationship she was involved in prior to diagnosis had ended, although they were still friends.

Kimberley: ...my friend is still there with me. But um...it's like, it's not the same any more. It's just time to move on and get out of this place and get out to a new area.

Since diagnosis, Kimberley had worked to re-establish ties with her children. Her son had been a source of encouragement and social support. Kimberley was planning to get accommodation away from her previous contacts and start afresh. She had withdrawn from her previous circle of friends and had only recently started socialising again with two close friends.

Kimberley: Yeah. I had a period there where we didn't see each other for a while...I could see changes in me...I just needed space is all. For a period now we're gettin' back together as friends, because they seen my kids and they seen them around with me, so they know I'm workin' towards gettin' the family back together and movin' along on accommodation and that, yeah, I just hadn't really focused on my illness. I don't know, or maybe I kind of hide it, I don't know, but to me now the other things are there for me to do and I'm not reminded of my illness until the appointment comes to see the nurses and the doctors. That brings home that it's like a reality.

KRYSTA

Krysta had been living with HIV for seven years. She tended to ignore it and tried not to let it affect her lifestyle.

Krysta: I got used to it now...

Interviewer: Is it less important now than when you were first told?

Krysta: That's right. It's not such a big thing now. I just get on with it.

She continued to drink regularly and socialised with friends and family. She did not have a regular partner, nor did she want one, but she enjoyed occasional casual relationships which had resulted in her having more children.

Krysta: Oh they ask me out, but I say no all the time.

Interviewer: So you don't go out with men because of your HIV?

Krysta: No, not that.

Interviewer: No, okay. You just don't go out with them because you don't feel like it?

Krysta: Mmm. Right.

Krysta had been subject to Case Management over a lengthy period for knowingly exposing others to the virus and she resented the control and surveillance aspect of Case Management, with people wanting to know about her “business”.

Krysta had her own accommodation, which she shared with relatives. She did not believe that HIV had changed her life a great deal.

Interviewer: In thinking over the whole experience of living with HIV, what’s been the most important, or the biggest change in your life?

Krysta: I don’t know. I really don’t know.

Interviewer: Do you think anything’s changed or is it just the same as it would be...?

Krysta: It’s the same.

Interviewer: You haven’t made any big changes in your life?

Krysta: No.

PAULINE

For Pauline, worrying about staying alive and what tomorrow may bring had more of a negative impact on her lifestyle than any of the physical effects of HIV. She had been living with HIV for around nine years at the time of interview.

Interviewer: What would be different about your life if you didn’t have that condition?

Pauline: I’d get on with my life, get my licence, go for a job, have childrens, get a nice house, whatever.

Interviewer: What is it about your condition that stops you doing those things?

Pauline: It’s not my condition, but myself. The more I’m thinkin’ ’bout it, I can’t do things. And I got no cash. I wanna save some money, get things for my house.

Pauline had disclosed to only a couple of close relatives and her partner, although she had ongoing contact with other HIV positive women whom she had met at a women’s retreat. She tended to socialise with close friends and family only.

Pauline: I cut down on drinkin’ now and stopped smokin’ drugs. I want to give my body a rest, try to conceive a child.

Pauline had wanted children for several years, but she had not been successful.

Pauline: It's hard to get a man to use a condom. And I don't wanna tell a man about me. And I do wanna get pregnant...so it's really hard.

Side effects from medications had caused hair loss and weight gain, which Pauline believed signalled to others that she had HIV. Other people were aware that HIV existed in their community, but they did not know the identity of those who were infected. Any illness or differences could set tongues wagging or suspicions arising and a whole lot of "guessin" took place as to who might be HIV positive. Pauline felt stigmatised and unattractive.

Pauline: Other people told them things and they don't really know. But this thing with the hair on my head and that...they lookin'.

The other aspect of this for Pauline, was the daily reminder to herself that she was HIV positive. She preferred to ignore it, but having to take medications, to see the physical signs from medication side-effects and having to keep regular medical appointments were all constant reminders.

Pauline: But I don't want to worry 'bout my condition and you have to think about it, talk about it when you come here.

When asked how HIV had changed the way she thought about the future, Pauline's response was:

Pauline: It don't matter. I try and keep my mind off it. I try not to think of it to let me down...Hopefully they can make up a cure for it.

BONNIE

Bonnie had been living with HIV for around ten years. She had weathered fear of dying, depression and alcoholism. She had learned to accept living with HIV and had a busy, happy lifestyle looking after her partner and children. HIV no longer dominated her thoughts.

Interviewer: How has HIV changed the way you enjoy yourself?

Bonnie: Well I take that right out of my mind and I go on with all the activities and work and everythin'. Yeah, just like all that and I just go and do what I wanna do, you know.

Bonnie was single when first diagnosed, although she had formed a relationship soon afterwards.

Interviewer: How did you deal with that, with your condition, in meeting a new man?

Bonnie: Well it was really hard at first. Yeah, I had a big think about it (laughs). I felt a bit lonely at the time, see. There was a big gap there. I decided that...well my sisters, they were married and it sorta made me feel outta place with singles. So I thought about...oh well, might as well get a man and settle down with him. Yeah, I told him everythin' bout myself and he said, "It's all right," he said he don't really care, usin' contraception and that. He really don't wanna use them on me, you know. So I said, "You wanna live with me then?" and he said, "Yeah." And today we're still together, over ten years.

At the end of the day, Bonnie did not believe that HIV had made a huge impact on her life. Her health was satisfactory and she did not require medications.

Interviewer: In thinking over the whole experience of living with this condition, what has been the most important change that's taken place in your life?

Bonnie: Nothin' really.

Interviewer: Yeah?

Bonnie: Nothin's changed me yet, not even the problem what I got.

When asked how HIV had changed the way she thought about the future, Bonnie did not believe it had.

Bonnie: Nothin' wrong with my future. Nothin' wrong with my activities and work around the house. Nothin' wrong with that. Everythin' is okay. Nothin' in my way is stoppin' me.

Interviewer: You sound very cheerful and happy.

Bonnie: Yeah, that's the way I like to be...happy.

Bonnie's final words at the conclusion of the interview:

Bonnie: I'd like to say I hope there's a cure for it. I hope one day it comes along. That will be the happiest thing in my life then and for everybody else.

DENISE

Denise tended to ignore her HIV status, although it did have an impact on her social life. She tended to socialise with close friends and family only, and reported that she had cut down on smoking and drinking. She was friendly with other women in her community who were HIV positive, with whom she had attended a women's retreat. Denise had been involved in a de facto relationship previously, but at the time of interview she was single and lived with relatives. She reported that she preferred to be single, admitting that HIV was a barrier to forming new relationships. She preferred not to disclose her status and was afraid of violence if she did so to a new partner.

Interviewer: What sort of things do you worry about?

Denise: Oh, telling them by myself.

Denise had had the help of an Aboriginal Health Worker when her previous partner was informed of her HIV infection.

Denise did not believe that living with HIV had changed the way she thought about the future. She had experienced sadness and depression when first diagnosed, but had learned to accept it and just get on with her life. She had been living with HIV for seven years.

FRANCES

Frances had been living with HIV for about five years. She was widowed and had health problems and disabilities unrelated to HIV. As an older woman, she had already lived a fairly full life before being infected. Her HIV status was known in her community and she had experienced discrimination because of it, but was philosophical in her attitude regarding its effect on her life.

Interviewer: Has HIV made a difference in your life?

Frances: No. Same way you all go, you know.

Frances had been infected as a result of exchanging sex for alcohol. She was in prison at the time of interview, but she reported that prior to this she had cut down on drinking, particularly hard liquor, but still enjoyed drinking beer regularly with her friends.

Interviewer: Does HIV make it hard for you to enjoy yourself or meet a new man?

Frances: My man finish a long time. Workin' man...

Interviewer: Are you single now?

Frances: I'm single now. Don't want no man. I only like good workin' man.

Frances was looking forward to being released and living in new Homeswest accommodation with a younger relative who was going to help care for her.

CAROLE

Carole had only been living with HIV for a year or so. She had moved back to a country town to reside with relatives and was still coming to terms with her diagnosis. While she reported that she had not made any big changes in her life and continued to drink and smoke as before, she had in fact taken steps to be re-united with her children, whom she had not seen for some time. She now also had stable accommodation.

Carole was single and was not planning any new relationships.

Carole: Don't want anyone.

Interviewer: What if you did meet a new guy? Is it hard to start the relationship and all that, you know?

Carole: Yeah. It is. But I wouldn't wanna start a new relationship...No, I'd rather be on my own, with my kids.

Carole did not know any other people who were HIV positive at the time of interview, but she was booked to attend a positive women's retreat. Her main sources of social support were family members, who were aware of her diagnosis. However, this was a double-edged sword, as it was also a source of hurtful insults during family arguments.

Carole: I just gotta live with it now. Except when my mother starts growlin'. It really upsets me.

(c) Fertility

Fertility: Male Research Participants

Ross was the only one of the four male research participants who had children. They were born prior to his HIV diagnosis. He was single at the time of interview and he had not seen his children for some time.

John had never had children.

John: No. I got none. It's a bit of a problem I suppose.

Interviewer: You would like to have some?

John: Oh, yeah. I thought I had a daughter, but she reckons it's someone else's.

Darren and Nick identified as gay and neither had had children.

Fertility: Female Research Participants

The sixteen female research participants were asked if they had children prior to and/or after HIV diagnosis. The results are outlined in Table 7 below:

Table 7: HIV and pregnancy in female research participants

| | | Pregnant at diagnosis | Subsequent pregnancies | Live births since diagnosis |
|---|---|-----------------------|------------------------|-----------------------------|
| Number of female participants with live children prior to diagnosis | 9 | 4* | 4 | 7 |
| Number of female participants with no children prior to diagnosis | 7 | 0 | 7** | 5 |

**One pregnancy was terminated*

***Two participants were pregnant at the time of interview*

Only three of the sixteen female research participants had no children at the time of interview. One regretted that she did not have any children, however she had found it difficult to form any new relationships due to her HIV diagnosis. Another had lost a child shortly after birth many years before and she was past childbearing age.

Pauline had suffered a miscarriage as a teenager and had been unsuccessfully trying to have a child for several years.

Pauline: I'm still lookin' forward to gettin' pregnant. I got tested for it, to see if the tubes are open or whatever. I gotta wait for the next gynae appointment for the result. I wanted a baby for a long time.

Four participants reported that they were pregnant when first diagnosed with HIV. Three resulted in live births, however Carmen was advised to have an immediate termination and a tubal ligation, which she later regretted.

Carmen: When I was first told, that's when, well my kids were grown up, and I really wanted another baby but when I had to get rid of it and they told me why, I cried and cried and I sort of like, I got in the shower and I thought I could wash it away, but I couldn't.

Interviewer: So you were pregnant when you were diagnosed?

Carmen: Yeah...Well at that time, they told me that I had to get rid of it, not had to, but it was either my life or the baby's, because they had no medications out then...

Interviewer: So that was for your health?

Carmen: Yeah. So I just thought well I may as well get rid of it and that is when they ended up tyin' my tubes and at that time I was confused, because now that I have got my tubes tied, I want a couple more kids.

Interviewer: So you were diagnosed and they took the baby away and you had your tubes tied?

Carmen: Yeah.

Interviewer: How long did that take, was that just like weeks?

Carmen: Well that was just all in one. Like they flew me to Perth, yeah. The next day or that night I went to theatre and everythin' happened all at once.

Carmen had enquired about the possibility of having the tubal ligation reversed. She had been advised that the operation would have to be paid for privately, as it would not be covered by Medicare.

Carmen: It would cost me...over two thousand dollars...

Interviewer: It is pretty hard to save that amount of money, isn't it? I suppose you have seen other ladies who are positive having babies?

Carmen: Well one of them I seen the other day...well she is on her third one and I know about her and she knows about me, and it makes me wanna have kids too.

Only one of the female participants was past childbearing age. Nine of the sixteen female participants had had twelve live births since diagnosis, with two of the nine giving birth to more than one child. All the women were prescribed antiretroviral medications during pregnancy and their babies were prescribed them for six weeks after birth. Eight of the nine women lived in rural or remote areas when pregnant. Two participants were pregnant again at the time of interview. None of the children born were HIV positive.

Jayme: I was actually worried that my baby would be HIV positive but he's not, so that's pretty good.

Seven of the nine participants who had given birth since diagnosis reported no problems during pregnancy or delivery. One participant reported having early contractions in the final months of her pregnancy which resulted in frequent hospitalisation, however the delivery was uneventful. Another participant was hospitalised during the pregnancy due to unrelated health problems which had existed prior to her HIV diagnosis and she required elective caesarean section.

This was the only delivery by caesarean section. One participant who had had caesarean sections prior to diagnosis, was pleased to have had a normal delivery with her last child.

Carole: For my other two I had a caesarean.

Interviewer: And did you have a caesarean with the last one?

Carole: No...I had it natural.

Relocation for delivery

In Western Australia, rural women who are HIV positive are advised to relocate to Perth four weeks prior to delivery at King Edward Memorial Hospital (KEMH).

Eight of the nine women who had given birth since HIV diagnosis reported that they had to temporarily relocate to Perth from rural areas prior to delivery. Five of them reported that this posed no problem for them.

Bonnie: Oh my de facto's mother stays down there in Perth, we stayed with them. Yeah, had a good life down there, doing our own thing, you know.

Three reported problems with relocation, which included loneliness; worrying about home and other children left in the care of relatives; and homesickness due to having to spend time away from family and friends. Tanya refused to relocate to Perth initially.

Tanya: ...they wanted to send me down south. Six weeks...it's too long. I said, "No, I'll be lonely." I wanted my de facto to go on the plane with me. They said no. I wouldn't go.

Interviewer: So what happened?

Tanya: I went down on the plane with my de facto two weeks before I had the baby. (Laughs). We came back on the plane too.

The titty-bottle

All the babies born to female participants had been bottle fed to reduce the possibility of HIV infection via breast milk. Participants were asked if bottle feeding rather than breastfeeding had made any difference to them. Seven of the nine who had had babies reported that it had not made any difference to them.

Interviewer: Was that a problem, not being able to breastfeed?

Krysta: No. The first kid was on the titty-bottle too. Didn't make no difference.

Interviewer: Did the doctor tell you not to breastfeed?

Yvonne: Yeah.

Interviewer: How did you feel about that?

Yvonne: It was okay. She was happy on the titty-bottle.

Tanya: I was bottle feeding him, but I was happy with it. Babies take a long time to get off the breast, so I had no problem.

Interviewer: Was there a problem with that, not breastfeeding?

Jayme: No, I really enjoyed it...Because I didn't have to get up and give the baby my tit, I just tell his dad, "Get up off your backside, make his bottle. I did what I had to do, you got the easy part."

Only two of nine women who had had babies since diagnosis expressed regret at not being able to breastfeed.

Carole: Couldn't breastfeed him because it would have went straight to him. That's what the nurses reckoned. They gave me pink tablets that dried the tit and he went straight on the bottle...

Interviewer: Would you have liked to breastfeed him?

Carole: Yeah, but I couldn't.

Interviewer: Did that create any problems for you?

Shona: Yeah it did. Like my friends askin' "Why don't you give the titty?" I say my nipples are small...or, "Look I am going to be drinkin', not a lot, but drinkin' now and then, so I'll put them on the bottle then I know it will be right for baby," yeah.

Shona hoped that researchers would come up with medication in the future that would make breastfeeding safe for HIV positive mothers.

Shona: ...but maybe if there was only one small special tablet? The only thing I can't understand, how could it get to the baby through the breast milk kind of thing? If they had one small special tablet maybe it would have been alright.

(d) Health care and access to HIV information and support services

Experience of health and wellbeing

Participants were asked to describe how HIV had affected their health. Three female participants stated that their health had not been affected by HIV.

Jayme: I really don't think it's affected my health at all. I mean I'm still a happy person. I get up and smile every day. I even smile at people that don't like me. (Laughs) I mean this illness is supposed to pull someone down. It's not doing a very good job on me, is it?

Seventeen participants described a variety of health problems (other than those due to the side effects of medications), which they attributed to HIV, outlined below.

Table 8: Health problems

| Health problems | Female | Male | Total |
|-----------------------------------|---------------|-------------|--------------|
| Depression/sadness | 7 | 2 | 9 |
| Fatigue | 7 | 1 | 8 |
| Stress/anxiety | 4 | 0 | 4 |
| Susceptibility to colds/flu/cough | 1 | 2 | 3 |
| Gynaecological problems | 2 | N/A | 2 |
| Boils/abscesses | 1 | 1 | 2 |
| Memory loss | 2 | 0 | 2 |
| Mood swings/anger | 2 | 0 | 2 |
| Fear of dying | 2 | 1 | 3 |
| Difficulty sleeping | 1 | 1 | 2 |
| Sweats | 1 | 0 | 1 |
| Weight loss | 1 | 0 | 1 |
| Loss of appetite | 1 | 0 | 1 |

None of the participants reported any major illnesses resulting from HIV. Most indicated that HIV had not made a great difference to their health apart from minor complaints, with depression and fatigue being the most commonly experienced health problems. The biggest impact appeared to be on emotional and mental health rather than physical.

John: ...if you didn't know you had it, you'd still be walkin' around, not thinkin' about it.

Kimberley: ...I don't feel like any different like I did before I got diagnosed. I actually feel the same as I did before I got diagnosed.

Olivia reported that she suffered from fatigue and was taking antidepressants. Her healthy appearance had resulted in some comments from relatives.

Olivia: ...they sort of expect that you're going to walk around real skinny and look sickly...I've known that someone has said to one of my closer relatives that you know, "She's lookin' pretty healthy."

Four participants had a range of health problems prior to their HIV diagnosis, which included deafness, diabetes, leg ulcers, arthritis, spinal problems, paranoid schizophrenia and physical disability from previous head injury and limb fractures. This resulted in health problems unrelated to HIV.

Strategies to maintain health and wellbeing

Participants described a range of strategies they adopted to maintain their health and wellbeing, which included improving their diets, reducing or ceasing substance use, smoking cannabis, exercising, maintaining normal activities, reducing stress, seeking prompt medical treatment when sick and participating in sporting/recreational activities.

Table 9: Health strategies adopted by participants

| Health strategies | Female | Male | Total |
|--|--------|------|-------|
| Reducing/ceasing substance use | 10 | 4 | 14 |
| Improving diet | 9 | 4 | 13 |
| Exercising/walking | 3 | 1 | 4 |
| Maintaining normal activities | 3 | 0 | 3 |
| Sport/recreation | 2 | 0 | 2 |
| Smoking cannabis | 2 | 0 | 2 |
| Seeking prompt medical treatment when sick | 1 | 0 | 1 |
| Reducing stress | 1 | 0 | 1 |

Kimberley was a long-term injecting drug user. She reported that she had reduced alcohol consumption, but she still smoked cannabis to help her relax, to reduce stress and to stimulate her appetite. John also continued to use cannabis as a relaxant.

John stated that his health had markedly improved since diagnosis, because he had been an alcoholic and had lived on the streets previously. Soon after being diagnosed as HIV positive, he had stopped drinking as a result of a court order. He also started eating healthy food and was employed for the first time in several years.

John: Well, see I was a chronic alcoholic. I was worse then, when I was drinkin'. My mother reckoned that my skin was just hangin'.

Ross and Bonnie also described themselves as “alcoholic” prior to diagnosis.

Interviewer: Can you tell me how HIV has affected your health?

Ross: ...well boils mainly. Because I’m alcoholic...well, trying to get off it now. The alcohol didn’t help my blood. And if you get bad blood, you get sores. And that doesn’t help you. Because of bein’ on the street before I came back home, I wasn’t eatin’ my food properly. I was eatin’ junk food mainly, no greens, nothin’. Just junk food and alcohol and cigarettes and that was it. So I’ve slowed down a lot now.

Bonnie: I was a alcoholic then. But, after that, when I found out I slowed down on it...I didn’t wanna lose my life so early...Sometimes when I get the urge to drink, I’ll drink a little bit. Not all the time. Not like I used to. I used to be a alcoholic, used to drink every day, never stop. Wines are no good for your body.

Two participants reported that they had been diagnosed after attending an urban Aboriginal Medical Service for alcohol counselling/rehabilitation. They had been given general health checks which included HIV testing.

Although some participants had reported heavy alcohol consumption as a coping strategy when first diagnosed, ceasing, or drastically reducing alcohol, tobacco or cannabis use was a common strategy for staying healthy in the long term.

Fourteen participants reported a marked reduction in alcohol use since HIV diagnosis.

Tanya: I’ve slowed down. Stopped doin’ things. I just look after my health...can’t even get drunk these days.

Interviewer: Why is that?

Tanya: It affects the virus...too much alcohol gets into the blood lines. The virus will be risin’ so I don’t drink no more to protect my health.

Interviewer: Can you tell me how you look after your own health?

Tanya: Go around, eat all I have to eat. Not junk. Good food and drinks.

Nick: I don’t drink and smoke any more, so that was a big change. (Laughs). But I miss smoking and drinking.

Interviewer: Has HIV changed anything about drinking?

Charlie: Yeah, I gave it up for six years.

Interviewer: Why did you give it up?

Charlie: I decided to just stop and take the medications. Stayed off it for six years.

Four female participants did not report any changes to their drinking patterns, which consisted of occasional binge drinking.

Carole: Yeah, I drink and I smoke, cigarettes and dope.

Interviewer: Has that changed in any way or do you still drink and smoke the same as what you did before?

Carole: Nothin's changed.

Two of the twenty participants did not drink, or drank very little prior to diagnosis and they reported no changes to this after diagnosis.

Medication

Not currently taking antiretroviral medications

Nine of the twenty research participants, two males and seven females, were not taking antiretroviral medications for HIV at the time of interview. Of these nine, the two males who had both been diagnosed for a year or less had never been prescribed antiretroviral medications.

Two of the nine had been prescribed antiretroviral medications previously, but had ceased taking them due to side effects such as vomiting, feeling ill, headaches and dizziness.

One of the nine had been taken off antiretroviral medications in the past because she did not take them regularly. She was subsequently prescribed them during pregnancy and stated that she had taken them to safeguard her baby, although they "tasted like cardboard" and were "yukky".

Four of the nine had been prescribed antiretroviral medications during pregnancy only.

Currently taking antiretroviral medications

Eleven of the twenty participants were taking antiretrovirals at the time of interview.

Six of these reported no side effects with their current medications.

The remaining five reported side effects with current medications which included panic/anxiety attacks, short-term memory loss, mild lipodystrophy, dizziness, headaches, insomnia and weight gain.

Five participants had had one or two changes of antiretroviral drug combinations previously. Nick reported that he was on his third regime and had gone from a total of fourteen tablets per day, to one in the morning and one in the evening. He suffered from dizzy spells initially and had given up work because he could no longer operate machinery.

Pauline reported weight gain, hair loss, insomnia and gastric upset with a previous combination of antiretrovirals.

Pauline: Well, I been takin' pills off and on. I sometimes take a break from it, 'cause it's makin' me get fat.

Interviewer: How do you feel right now? Do you have any side effects from your pills?

Pauline: Don't feel good. I had side effects from the first lot of pills...gastric upset. The second lot okay...The last ones, they too big. I couldn't sleep and they were too heavy on my brain. They changed them. They all in one now and it's okay...The worst thing was when my hair was fallin' out one time through takin' HIV drugs. It was embarrassing. People had some idea 'bout my condition because of it.

Interviewer: Do you have any problems keeping your pills around the house?

Pauline: Yeah. I hide my pills. I don't want people to know what they for. Don't want people askin' questions 'bout them.

Pauline felt stigmatised due to her hair loss and weight gain. She believed that her appearance signalled her HIV status to others, in the same way that lipodystrophy can be read as a physical marker of HIV infection (Persson 2002). This made her feel different and unattractive.

Social effects of HIV medications

Apart from the side effects of HIV medications, other problems in taking medications included forgetting doses, having to hide medications and alcohol consumption.

Missed doses

Five participants reported that they sometimes forgot to take afternoon or evening doses of medication, particularly if they were not at home. Morning doses did not appear to pose as much of a problem.

Two participants used dosette boxes. One participant used a mobile phone alarm, which was programmed to remind her to take her medications.

Shona reported that she doubled up on tablets if she missed any.

Shona: Like if I missed a day or two I would double up on them tablets, three times all together.

Concealing medications

Six participants reported that they had hidden their medications because they did not want to be questioned about their reasons for taking medication or to have others guess their HIV status. Three of the six stated that they no longer had to hide their pills since disclosing to family members. Another participant reported hiding her pills, but this was to prevent her young children from gaining access to them.

Shona, who had taken medication only during pregnancy, had told her mother that she was being treated for anaemia when her mother queried her about them.

Kimberley had started using a handbag to carry her medication and mobile phone. Her friends had never known her to use a handbag before and they were curious to know what was in it. She was uncomfortable because the handbag drew attention and she did not want others to know her HIV status.

Kimberley: Because they've never known me with a handbag. The bloody handbag was to remind me to put my medication in when I go to the hospital pharmacy...And the first time I walked down the street with a big brown paper bag, they said "What's in it?"

Alcohol use

Frances reported that she still liked to drink alcohol, but not until after she had taken her afternoon medication.

Interviewer: If you are drinking, do you still take your medication?

Frances: Yeah, but I don't drink until I take that last one. Then I have a drink...No wine, no spirits. Long time ago I used to drink them, but not now. Too strong for me.

Interviewer: Have you changed the way you drink because of your condition?

Frances: Yeah. I don't drink until I had my medication. Only just beer, don't drink all that strong stuff.

Krysta and Darren reported missing doses of medication when drinking.

Interviewer: Is there anything that stops you taking the tablets?

Krysta: Drinkin'.

Interviewer: So do you have a little break from your tablets when you are drinking?

Krysta: Yeah.

Interviewer: Once a week you have a drink? So you stop taking your tablets just that day, or a couple of days?

Krysta: Yeah. Yeah, a couple of days.

Darren: ...well, at first when I started I was drinkin' and all that, so you know it wasn't...yeah, I missed a lot of the dosages, but after that I tried to improve a bit better.

Jay reported that she too stopped taking medication when drinking, but took extra doses until she caught up.

Interviewer: Is there anything that stops you taking your pills?

Jay: ...if you had a hard night out it stops you. But you know, you make it up until...you don't double your dose but you take your one dose again, you don't double it...until you catch up.

Nick, who had more contact with the Western Australian AIDS Council and awareness of treatment options, felt that Aboriginal people's lifestyles, accommodation and diet were not adequately taken into account when prescribing antiretroviral medications.

Nick: ...build the treatment around the client situation rather than give the treatment saying you have to turn your life round to suit the treatment...Like knowing that they are only going to be able to take the drugs once or twice a day, rather than three times a day at seven-hour intervals. Give them the right medication to suit their lifestyle, or suit their drinking habits or their food intake sort of stuff.

Participants' views of health care provision

Eighteen of the twenty participants had travelled to other locations since diagnosis. These ranged from short visits to other towns or communities (such as interstate visits to visit family, to attend conferences or for employment and study purposes), to relocation from one rural area to another or between urban and rural areas. As a result, participants had accessed health care services from a variety of sources. (A detailed description of arrangements for HIV health care in Western Australia is provided at Appendix 3). The two participants who had not travelled to other locations since diagnosis both lived in the metropolitan area, and had been diagnosed for less than a year at the time of interview. None of the participants reported relocation for the purpose of accessing day-to-day HIV health care services, although pregnant rural women moved temporarily to Perth a few weeks prior to delivery in order to access specialist obstetric care.

In general, whether they resided in metropolitan or rural areas, participants expressed a high level of satisfaction with the type and standard of care they received.

Ross: Oh, it's great, yeah. A good bunch of people down there. Yeah, very supportive...Ah, yeah. I can go there and have a talk with them anytime I feel down. Yeah, everything really...like if I run out of medicine I just go and get some more medicine. It's always gonna be there, not gonna say no to me or nothin' like that...It's good that I know that they're there to help me.

Jay: They are a cheery mob. "Hello, good morning, what you doing?" They got that little happy...they've got the boost there. You know you may be down on your dumps and everything like and they see you come for an appointment and you sit back and you readin' a book. You're up there and next minute, "Hey, how you been keepin'?" you know. They give me that little booster.

Some received care from a variety of health care providers, including public sector health services in the community and hospitals, Aboriginal Community Controlled Health Services, general practitioners and the Western Australian AIDS Council. Most participants preferred to limit the number of people knowing their HIV status so restricted their use to a few services for care related to their HIV infection.

The health services that participants spoke most highly of met their emotional, social and welfare needs, and not just their medical needs. Health services that were seen as most user-friendly provided an informal, comfortable environment, continuity, privacy, and culturally and gender appropriate programs and services. Those with a low staff turnover were seen as more conducive to building trusting relationships with Aboriginal people who are HIV positive. Confidentiality was always considered to be of the utmost importance.

Participants were particular about where they accessed health care in relation to their HIV infection. For example, one participant accessed a remote area clinic only if she required treatment unrelated to her HIV status. She would only access care relating to her HIV infection there when the health professionals who knew about her HIV status were visiting the clinic, but otherwise would travel into town to access treatment there. Other participants reported accessing care from Public or Community Health Nurses in rural locations and being satisfied at the treatment received.

The physical environment of the clinic and a personal/emotional connection with staff were both important issues in receiving care. The environment at one teaching hospital was not considered to be particularly comfortable for Aboriginal people.

Jay: I guess there is not much Aboriginal people...When I go along for appointments there is only one little Aboriginal person and she's too shy. She just like hidin' herself in a magazine. When her name comes up, well she looks, "Oh...she knows my name." Oh yes I know her name now, you know. They get that frightened.

To avoid the alienating environment of the teaching hospital, Olivia suggested that a suitable person, perhaps a person who was HIV positive, could visit Aboriginal people in their own homes. There they would feel more relaxed about asking questions and gaining information. Alternatively, a place could be set up at the hospital where the atmosphere was conducive to this and was user-friendly for Aboriginal people. Olivia thought more one-to-one support and the provision of more information regarding HIV were needed.

Participants expressed a variety of opinions related to accessing HIV care through the local Aboriginal Community Controlled Health Organisations, (commonly referred to as Aboriginal Medical Services or "AMS" by participants). Only three participants regularly used an Aboriginal Medical Service, and twelve of the twenty participants had not accessed health care at an Aboriginal Medical Service since their diagnosis.

Two major reasons were given for not accessing care through Aboriginal Medical Services. The first was a high level of satisfaction with the care provided by other services, so that participants felt that their needs were being met.

The second issue identified by a number of participants related to concerns about privacy and confidentiality, particularly concern about other Aboriginal people becoming aware of their HIV status. These concerns occurred, but were not restricted to, when members of the extended family were employed there. In general, these concerns were not based upon breaches of confidentiality, although two participants did identify specific concerns with confidentiality that had affected them. For example, Bonnie reported that some people in the Aboriginal community knew her HIV status. As she had not disclosed to them herself, she strongly suspected that it had come from Aboriginal Medical Service staff.

Bonnie: It's supposed to be confidential every file. But all the Health Workers there, they go right through your file and they tell anybody about your problems.

Jay reported that Aboriginal Medical Service staff had disclosed her HIV status to other members of the Aboriginal community, which caused her shame and embarrassment.

Jay: But the people, like they go along lookin' through the files and they go along, talk to one and then the one will talk to the other and it's like being a grapevine...I'm too shamed to go to AMS. Even if I walk past them, I go right around the block. And if I go past in the car there, we speed up...through, you know.

A number of other participants made it clear that their relationship with their health care provider was extremely important to them, expressing the desire for a small number of trusted professionals to provide continuity of care and ongoing support. Many referred to their relationship with individual carers.

Jayme: Yeah, well the social worker at Royal Perth, she's been working with me ever since I found out that I was positive. And like she's not only been my counsellor, but my best friend too.

Interviewer: Right. You still keep in touch with her?

Jayme: Yeah, yes I do. Whenever I go down to the clinics or to the hospital at Royal Perth, I always call her up and sit and have a chat and everything.

Frequent staff changes were cause for anxiety. Trust and confidence, even in a service that has been used and trusted for years and where a person is satisfied with the health and medical services received, could be undermined when the personal bond with a trusted staff member was lost.

Tanya: I just don't like coming here any more. Auntie's not here. It's not confidential any more.

Interviewer: Has anyone here ever told anybody about you without getting your permission?

Tanya: No.

Interviewer: When you say, "It's not confidential," what do you mean by that?

Tanya: Too many new people coming in all the time. More people gettin' to know about me. It's not like before, when you would see the same people all the time.

Interviewer: So are you talking about too many staff changes?

Tanya: Yeah. Some of us womans don't come in any more. Not like before. We only come in when we get sick...I would like it how it was before. I just miss the one person, Auntie.

Participants spoke highly of the services they received, particularly those which provided holistic care and recognised the many factors, other than their HIV infection, impacting upon their lives. The types of services they talked about included ongoing health and medical care, support, counselling, transport, home assistance, advocacy, food vouchers, access to temporary accommodation, positive women's retreats and assistance with travel to other regions.

Pauline: Yeah, I get support there. They got accommodation now...I visited somebody there. Yeah. It's good. People got someplace to go now...this place doin' okay around here. They up to date with people and medications. See how they goin' with their lives and that.

Carmen: Yeah, like transport and everything, like if you haven't got no transport they will come and pick you up.

Interviewer: Right, yeah.

Carmen: Like this is right, where it is. The place itself.

Interviewer: Right. So, it is in a good location?

Carmen: Yeah.

Interviewer: So you get your health treatment and you get a bit of support from the staff here, you get transport to and from, and you get your medications. Do you have to pay for them?

Carmen: Nup.

Interviewer: You get them free. So, it is pretty good all round then?

Carmen: Yeah.

Frances reported that as well as medical treatment, she was given assistance with showering and had some of her belongings stored at the local Aboriginal Medical Service while in prison.

Frances: You can have a shower, clothes washed. They good.

For those who had not disclosed their status to anyone, health professionals were often the only people they confided in.

Interviewer: Does anybody provide support for you, somebody to talk to?

Yvonne: Yeah, the doctor and other workers there.

Where participants did not establish a good rapport with their health service provider, their satisfaction with care diminished. For example, one participant felt that although his medical needs were met, clinic staff were not interested in discussing personal or emotional issues.

Darren: I've tried to bring up some stuff, things, how I feel and that. I think I bring up some personal stuff, but I think they're not interested in that. I know that.

One participant described being "rough-handled" at a colposcopy to which she had been referred. After this painful experience she was adamant she would not return to that particular clinic but would seek care elsewhere, where she considered the staff to be more considerate.

Ten of the sixteen female participants had received treatment at King Edward Memorial Hospital for Women and all were satisfied with the health and medical care they received. One participant spoke very highly of the staff there and stated if she was sick, she would rather go to "King Eddie's" than anywhere else. Another participant referred to a minor negative incident in the labour ward, although she was otherwise happy with the treatment received.

Travel from rural areas for specialist appointments

Eleven of the fourteen rural participants received ongoing HIV health care locally, with HIV specialists making three-monthly visits to the region. The remaining three rural participants travelled to Perth.

None of the three rural participants who regularly travelled to Perth for their three-monthly specialist appointments minded the travel. For Jay, it was an opportunity to let her hair down, have a bit of a holiday and a drink with old friends, away from the moderating influence of her family in the country.

Jay: I'm up and down for appointments...But sometimes I take it overboard because I'm here for...I'll say I'm up here for two days, but then I stay a full week.

When asked if she would prefer to have specialist HIV health services in her own town rather than travelling to Perth for appointments, Jay expressed a preference to travel to Perth because she was already known to the staff there and her medical records were there.

Jay: Well in a way it gives you a bit of a break too...But then there is so much people that come up here and your file is here and that's the main place that you...you know, most of your medication and everything, they know who you're talking to, because instead of having one down south or up north, there they know you.

Case Management

The Department of Health in Western Australia includes a Case Management Program under the Communicable Disease Control Directorate, which works with people who are HIV positive and exposing others to the risk of infection. Case Management staff do not provide clinical services, although they may facilitate appointments with health service providers. They provide ongoing counselling, education and support to clients to assist them to modify unsafe behaviours. Case Management includes a statutory component in implementing the provisions of Western Australian health legislation. There are different levels of Case Management, from low to intensive.

Fourteen of the twenty participants had been referred to the Case Management Program since diagnosis. It should be noted that Case Management, particularly in the regional area of special need, has adopted a broader welfare role, and participants report receiving assistance with bus passes and transport, counselling, social support and advocacy with other agencies regarding housing, pensions and access to children.

There was not a unified view about the services of the Case Management Program. The negative aspects included monitoring of sexual behaviour, perceptions of too much control over clients' behaviour, and uneasiness at the coercive element in ensuring compliance with the *Health Act*.

Krysta: ...Too much control. I don't like that. People wantin' to know about my business.

Another issue for rural participants was the sense of being easily observed. Remembering back to the time when clinical staff in their region had case management responsibilities, some participants described how these dual roles created barriers for them in accessing health care. For clients, the feeling that their behaviour was under surveillance, coupled with being collected in a Health Department vehicle, caused anxiety.

Carmen: Well it was hard for me and like I didn't know where to run, or I didn't know where to wait. Sometimes I used to wait out the back, stand up and look and wait, because someone would say, "Oh we need to see you" and I would sort of panic...Yeah, sometimes in the community what we have got, I hear a lot of people say, "Oh we know that car, people in that car, they all HIV mob," you know and that is why when I need to come in here, I say, "Oh I will find my own way," or if not, I will wait out the back or somethin'.

The separation of a case management function from that of clinical care in the area of special need in 1998 with the institution of a dedicated Case Management position, improved the acceptance of health care provision and appreciation of the case management role. For many participants, after some adjustment and with time, a clearer understanding of the service emerged.

Once the sense of initial intrusion was overcome, support from the Case Management Program helped with access to a range of health, social and welfare services, meaning the service was acknowledged as providing useful support.

Carmen: Like at first they was kind of watchin' people, you know, what they was doin' and what they was hearin' you know? In a way it was, but now I think it's...eased off.

Pauline: Not so much now, but before. Sometimes there was too much control.

Shona: Oh at first, when they kept gettin' in contact with me and all that, it pissed me off, but now they see me only when they need to. Yeah, and that's fine by me.

Participants' suggestions for improvements to health services

Participants were asked how health services could be improved for Aboriginal people who are HIV positive. Twelve of the twenty participants replied that they were satisfied with the services currently provided and did not offer any suggestions for improvement. Eight participants suggested strategies for improvement of health care provision.

Metropolitan participants made the following suggestions:

- Provide more information regarding HIV.
- Make health services more holistic, more user-friendly for Aboriginal people to meet social and emotional needs as well as medical needs.
- Provide a separate room where Aboriginal people feel comfortable, with HIV information readily available or an outreach service for this purpose.
- More social support by having camps, taking people out, travelling. Mixed groups of people who are HIV positive, not restricted to Aboriginal people.
- Mainstream services could be more culturally aware and employ Aboriginal Health Workers. Gender differences need to be recognised in providing sexual health information and training in a culturally sensitive way to Aboriginal Health Workers. They may have to have separate groups.
- Take into account housing, travel, food and general living conditions when providing treatments to Aboriginal people who are HIV positive. Build the treatment around the client's situation rather than clients having to turn their lives around to suit the treatment.
- Give medications which suit the client's lifestyle, drinking habits and food intake, instead of standard treatments that may be difficult to adhere to. Medications once or twice a day only, not three times a day at seven-hour intervals.

Rural participants made the following suggestions:

- Have educational activities that include partners of HIV positive people. Build a family house in the region, out of town, with a "big screen" where people can go for activity days, or to relax and where people can be educated about HIV.
- Have a hostel in Perth where country people could stay when attending medical appointments. Have a counsellor available, or have camps where Aboriginal people who are HIV positive can get together to talk.
- Provide local HIV services in distant regions, e.g. the Kimberley, so that people do not have to travel a long way for medical appointments and be away from their communities for a week.
- Try to retain staff and not have a high staff turnover.
- Provide more respite accommodation. There is insufficient access to existing rural respite housing.

One rural resident thought that the local Aboriginal Medical Service could be improved, although she did not access it for HIV health care. She suggested that the service could build a bigger and better building, with improved equipment and a more proactive approach to health promotion, including sexual health, alcohol misuse and violence in the community.

The majority of improvements suggested by participants related to accessing information or the cultural and social aspects of living with HIV, rather than the medical or clinical aspects.

HIV services

Participants were asked how services, other than health services, could be improved for Aboriginal people who are HIV positive. Ross suggested providing hostel accommodation.

Ross: You could have a few places more for HIV positive people. Like me, I'm lucky I could come home to my mother's place because a lot of people can't. They're either passed away now restin' peacefully, or they're not welcome there no more. They feel rejected, most of them. Then they found the streets. They just think no-one wants to help them, but there is people that want to help.

Interviewer: So what sort of things would help them?

Ross: Accommodation mainly. I reckon if you want to find out anything, you have to be settled. If you're not settled you're going to go to a seminar, listen to it, take the advice, take it in, but then where you gonna go? Back to the park, drink again and that's all going to be drunken out of your mind then, washed outta your brain. You won't know what you're doin', what happened, what was said. But if you got a place to go, then you can take that home with you, think about it, you know.

Interviewer: So, accommodation?

Ross: A hostel. For Aboriginal people with HIV. Mixed hostel, so you can hear both sides...Aboriginal. Men and women. Hear that story, man story, hear woman story, hear the young story, hear the old story, you know.

Jay also suggested having a hostel or arranging camps where people could meet.

Jay: There's a lot of people that live in the communities like up north and down south and over east, which they want to get away from their own community because of all the stigma. You could have like a hostel, like when they have appointments here [*in Perth*] the main ones, and at the same time like counsellors. Have like camps where people come along and talk. Meet up with other blackfellas who are willing to come along, they can talk with them...Aboriginal people who are HIV positive.

Shona and Charlie also suggested taking people away together on camps or trips.

Despite residing in an urban area where services were readily available, Olivia appeared to be the most isolated of the participants. She had not met any other Aboriginal people who were HIV positive and she had the least knowledge of the services available. She suggested having either a drop-in place where Aboriginal people were comfortable and could share experiences, or a type of outreach service where people could be visited in their own homes.

Four rural participants reported that the current services provided in their region were satisfactory and met their needs. Two of them mentioned that respite accommodation had been built in their area, specifically for Aboriginal people who are HIV positive. Another participant from the same region complained that there was not enough access to the respite accommodation.

Tanya: Yeah, accommodation for people who really needs it, not just wants it. I asked about the house down the back. It's always booked. I wanted to stay there a couple of days, to get peace and quiet...there's not enough access.

Three other participants from that region stated that transport was a problem and that a bus service was required.

Yvonne: Yeah, one thing that would be better is a bus service to the community. It's too expensive for people to pay for taxis. There should be a bus service.

Six participants, two rural and four metropolitan, had received support or assistance from the Western Australian AIDS Council (WAAC). Five of them had contacted WAAC on one or two occasions only.

Nick had regular contact with WAAC as he provided peer support and public speaking services from WAAC in addition to working as a volunteer.

Olivia, who was a very shy person, had only recently contacted WAAC for assistance. She did not feel very comfortable in visiting their office, although she appreciated their support.

Olivia: I think at first I was a bit uneasy, like it was something...how can I say it? Because it was an AIDS Council and it was like something positive you know, like something you have to face, you know, that's right in front of you.

Pauline had received peer support from a non-Aboriginal woman who was HIV positive via WAAC, while in Perth temporarily when travelling between country towns. She enjoyed the contact.

Pauline: I would like to meet more people like her, can ask them about their life, their feelin's, what they wanna do.

Interviewer: So would you prefer to talk to wadjallahs? [*whitfellas*].

Pauline: Yeah. But not just Perth. Another state. Darwin, Northern Territory, Queensland, Sydney, people all over the state. Mix in with others, Aboriginal mob too over there, so they not on their own.

Interviewer: Do you think Aboriginal people with this condition feel alone?

Pauline: Yeah, they do.

Jayne contacted WAAC once when she was temporarily in Perth awaiting the birth of her child.

Jayne: Yeah, that's when I was having a rough patch with money and I phoned them and I told them my situation and everything. They actually helped me out with getting some money and some things for myself. When I had my baby they actually came with a baby pack. Photo album, baby clothes, baby bath and everything in it.

Jayne had regularly stayed at a women's hostel/refuge when travelling to the city for medical appointments.

Jayne: Well I've been coming here since I was sixteen years old, to this one hostel and they seem pretty good with me, the workers here. I mean the people that come in here don't need to know about my situation, but the workers do and they're very supportive.

Kimberley had received assistance from WAAC and she also received meals and support from a community agency.

Jay thought that services for Aboriginal people who are HIV positive were satisfactory in relation to housing and disability allowances.

Jay: ...gonna need disability pension and things like that. There is special housing, like they put you on a priority list and they give you six months same as like a person who is on dialysis or a person who has been, you know got something wrong with their hip.

Interviewer: So you reckon that they do quite well already, do you reckon?

Jay: Yeah, I reckon.

John knew that he was eligible for a disability allowance and housing due to his HIV status, however he lived in a country town and was unwilling to disclose his status to local workers at the Department of Housing or Centrelink.

John: I'm finding it hard now, trying to get on the invalid pension...So I can get a flat, move into a flat. But I can't see how...I can't get a pension even.

Interviewer: Have you been over to Social Security?

John: Well, what are they going to say about me? I tried them, but am I goin' to say that to Social Security? How am I goin' to say that? Can you put me on the pension? They want to know how I want on the pension.

Participants were asked where they obtained HIV information. Sources of information are outlined below:

Table 10: Main Sources of HIV Information

| Main sources of HIV information | Number |
|---|---------------|
| Health service in regional area of special need | 12 |
| Royal Perth Hospital | 4 |
| Fremantle Hospital | 2 |
| Rural Registered Nurse | 1 |
| HIV specialist GP/WAAC | 1 |

Information from the above sources included information regarding treatments, HIV management, and living with HIV for 19 participants. The remaining participant, a metropolitan gay male, mainly obtained information regarding HIV management from his HIV specialist GP, while his main source of information regarding treatments and living with HIV was WAAC.

Five participants named secondary sources of information, outlined below:

Table 11: Secondary sources of HIV information

| Secondary sources of HIV information | Number |
|---|---------------|
| Royal Perth Hospital | 2 |
| Perth Case Management Program | 2 |
| Rural GP | 1 |

(e) Health promotion and education issues

Participants' suggestions for future education of Aboriginal communities

Suggestions for educating the Aboriginal community regarding HIV included the following responses:

Nick: They should know that it's prevalent actually, and I think also having a face put to it, an Indigenous face to the virus. That's why I try and do public speaking as much as I can. Just saying I'm from the same sort of community and it affects us.

Darren: They've just got to be cautious. It's not just a gay thing. I mean everybody loves sex and everyone does it you know, regardless.

Jay: Yeah, like put on a play and have someone, you know? That goes out like to schools, and out to TAFE, you know TAFE courses? Goes out to the communities and like put on a sketch or somethin', put a play on. Make it laugh and then at the same time be serious about their...you know, get condoms, you know, all havin' fun when you have that...

Several participants suggested having Aboriginal HIV positive speakers talk in schools and at community meetings. One participant suggested having an HIV positive speaker talk to young people at school from Year 6 through to Year 12.

Jayme: Well what had a lot of effect on me was somebody spoke to me and they were positive. And I thought, you know, I'm not positive. Well at the time I wasn't positive but I was thinkin' you know how lucky I was not to have that disease at the time. And I thought to myself, well I'm goin' to do the right thing.

Interviewer: So somebody told you before?

Jayme: Yes, I actually met a member of my family who was positive. He was sayin', "Make sure you use these balloons if you're going to get a boyfriend because you don't want to end up the same way I did. And I said to him, "Why, what's wrong with you?" He said, "I'm HIV positive." I didn't really understand what that meant then, but as I got older, as I just started gettin' interested in boys and he told me that. So I went home with all hickeys on my neck, and you know, boys' names written all over my hand and whatnot. And he sat me and my cousins down, then he gave us a ear-bashin'.

Jayne reported that she generally used condoms as a result of her HIV positive relative's influence, but added:

Jayne: ...the mistake I did was to have unprotected sex once.

One of the common themes identified in participants' responses was concern for young people who are sexually active from an early age without being aware of the consequences, namely sexually transmitted infections and early teen pregnancy. Some participants stated that Aboriginal adults already know of the dangers of contracting HIV due to previous education campaigns in their communities, however they believed that there has been a lack of education for young people who are beginning to be sexually active now. They identified a need for continuing HIV awareness campaigns targeted at primary school aged children before they start to inject drugs or to become sexually active.

Interviewer: What do you think the Aboriginal community should know about HIV?

Tanya: A lot. For the young ones...they should know about protection. A lot of young girls need to be told about it. Teenagers...there's one...14 years old and pregnant.

Interviewer: What about adults in your community? What should they know about HIV?

Tanya: They most probably know all about it.

Interviewer: What would be the best way of telling kids about it?

Tanya: Get 'em all together in one big room. Get somebody to talk to them. How you catch it...how it spreads. Show a video of the virus. Show them what it's like, from day one, from when it gets in until you pass away, things like that.

Bonnie: ...in our community there is nothin' that's being told here. Couple of years ago it did. They need to start it up again. For younger kids, because I see a lot of kids before they get to high school, about grade 7 and first year, they need to be told about it. 'Cause they startin' it then, you know. When they get drunk they out on the street, those kids, and they watch one another and that's what makes me think, oh they goin' to end up gettin' the same thing what I got...

Interviewer: What about educating them about HIV? What kind of things do you think the kids need to know about it?

Bonnie: They really do need to know about it. The parents should tell them and it should be a person there who got it, should tell them, what it does to them and how it affects them.

Interviewer: Now, what about adults in the Aboriginal community? Do you think they need to know about it?

Bonnie: What the older ones? They know, they really know everythin' about it.

Pauline: Everybody should encourage young kids. Just to be on the safe side.

Interviewer: What would be the best way of doing that?

Pauline: Through the schools. Use videos and those instruction models.

Interviewer: Do you mean like those plastic models of the womb at public health?

Pauline: Yeah. Them things.

Interviewer: What about adults? What should they know about HIV?

Pauline: Adults already know. They don't need it. Just the kids.

Jayne reported that she knew of young people under 15 years who had contracted sexually transmitted infections, and she believed there was not enough education in her community regarding HIV or sexual health. She added that there appeared to be little interest from health educators, or visits by Health Department staff to the area, the exception being in relation to Case Management or contact tracing.

Jayne: I mean the only time we get people comin' around like that is when someone like me is in trouble for havin' unprotected sex, or you know, if somebody finds out you got this illness or another illness...and that's the only time I used to get visits from the Health Department, is when I had unprotected sex.

Jayne's view was that there was too little action in relation to primary health prevention and health promotion programs in the community and too much emphasis on the diagnosis and treatment of sexually transmitted infections after they have occurred. For Jayme, this meant pressure to comply with Case Management requirements.

Two participants did not want HIV to be a continuing topic in their community as they did not want constant reminders of their HIV status and they worried about other people finding out their status.

Interviewer: What do you think the Aboriginal community should know about HIV?

Karina: I don't know.

Interviewer: Do you think kids should know about safe sex?

Karina: The school teaches the kids that already.

Interviewer: What about adults in the community?

Karina: They know too much about it already. They should leave it. They all know.

When asked what things the Aboriginal community should know about HIV, this was John's response:

John: Best thing...first thing to do is know your partner, I suppose. That's the only thing that you can do, if you don't want to catch it. Don't share drugs, needles. We all know that, the common basic things.

Interviewer: Okay.

John: See I know that [laughs]. I don't know, I probably got it havin' sex.

Interviewer: Right. Did you know you could get it that way before you got it?

John: Yeah, we all know.

Participants' suggestions for future education of Aboriginal communities about HIV are summarised below:

- HIV positive Aboriginal speakers to tell their stories at community meetings, in schools and on videotapes
- Community education meetings
- Sex education at primary school level, well before young people become sexually active
- Education in schools and clinics regarding early teen pregnancy
- Education regarding injecting drug use, particularly for youth
- Comprehensive HIV education including modes of transmission, susceptibility to other infections due to impaired immune system, replication of HIV cells in the blood, physical, emotional and social effects of living with HIV
- Education regarding the difference between HIV and AIDS
- Education to dispel ignorance of modes of HIV transmission (e.g. you can't catch it from sharing plates, touching or hugging an infected person)
- Distribute Aboriginal information booklets like *HIV/AIDS & Us Mob*
- Education regarding the links between alcohol, violence and sexual health
- HIV health promotion and awareness theatre, plays and sketches that entertain the community
- HIV and pregnancy
- All at risk, not just a "gay thing"
- HIV prevalence in Aboriginal community
- Develop local programs in partnership with community elders that can then be directly used by elders in their own communities
- Videos, posters and leaflets
- Provide and update posters, leaflets and pamphlets in remote area clinics and fringe communities in towns
- Aboriginal Health Workers and other health providers to regularly visit and talk to remote communities about HIV
- Provide more recreational outlets for Aboriginal youth with sexual health promotion and condom availability
- Provide Aboriginal cultural recreation outlets for youth, involving creative arts
- Television campaigns
- Information on how to cope with HIV, how to access confidential support
- Know your partner

The four most common suggestions for educating the Aboriginal community about HIV issues, were to provide sexual health and blood-borne virus education to prepubescent youth; to have HIV positive Aboriginal speakers; and education to dispel ignorance of modes of transmission; and the difference between HIV and AIDS.

5. DISCUSSION AND RECOMMENDATIONS

This research was initially framed as a qualitative comparative study between the experiences of Aboriginal people living in rural and urban settings. The rationale for this was that around half of the Aboriginal people in WA who have been diagnosed with HIV live in rural areas and half in the metropolitan area. As well, a distinct model of health service provision had been developed for a cluster of HIV positive Aboriginal people living in one particular area (designated as the regional area of special need), with additional resources from both state and federal health departments for their care and support. Examining social, cultural, geographic or other possible barriers to effective health care for Aboriginal people who are HIV positive was an important component of the research.

In practice, a rural/urban comparison of experiences proved to be an artificial distinction due to the mobility of the participants who did not fit neatly into a rural/urban dichotomy. Moreover, all research participants, both rural and urban, received regular medical assessment and advice on HIV management from the tertiary hospitals, two from Fremantle Hospital and the remainder from Royal Perth Hospital. For the purposes of this study, research participants were classified as rural or metropolitan residents according to their usual address at the time of interview. Perth and Fremantle residents were classified as metropolitan, while those from all other regions of Western Australia were classified as rural. While some of the latter resided in remote communities, regions and towns have been discussed in general terms only, so that Aboriginal communities are not identified.

Findings from the research are discussed under the following headings:

- (a) Characteristics of research participants
- (b) Experience of living with HIV
- (c) Fertility
- (d) Health care and access to HIV information and support services
- (e) Health promotion and education issues

(a) Characteristics of research participants

From a population of forty-four Aboriginal people who were HIV positive and known to be living in Western Australia during the research period, twenty were interviewed. The majority of the research participants were young (average age 32), female (16:4), heterosexual (18:2) and resided in rural areas (14:6). Eleven of the rural participants resided in the regional area of special need, with only three residing in other rural areas and six in metropolitan areas.

Insight into the impact of HIV on people throughout Australia has been provided by national surveys of people living with HIV/AIDS undertaken by the Australian Research Centre in Sex, Health and Society (ARCSHS 2004). The six major content areas of the surveys were health and treatments, sex and relationships, accommodation, employment, community involvement and finances. To date, three mailed surveys have been undertaken: HIV Futures I (1997), HIV Futures II (1999) and HIV Futures 3 (2001). The size and sampling profile of the HIV Futures surveys (ranging between 6% and 8% of Australian PLWHA) have enabled comparisons between different sub-populations and different states of Australia and have provided information for policy makers and service providers.

The HIV Futures 3 Regional Report for Western Australia (Grierson & Misson 2002) and the HIV Futures II Report on Aboriginal and Torres Strait Islander people living with HIV (Willis et al. 2002) have been used for comparison with the current study population.

Of the 894 PLWHA who responded to the HIV Futures 3 Survey in 2001, sixty-three were from Western Australia (Grierson & Misson 2002). The average age of Western Australian respondents was 39.7 years, somewhat younger than respondents from other states (43.1). 87% were male and 13% were female. Likely mode of transmission was cited as homosexual or bisexual contact for 76%, heterosexual contact 11%, contaminated blood products 7%, injecting drug use 3%, combined homosexual/bisexual contact and injecting drug use 2%, and 2% did not know how they were infected. All but one of the Western Australian respondents lived in Perth.

Separate results for the fifteen Aboriginal and Torres Strait Islander people who responded to the HIV Futures 3 Survey nationally were not available at the time of this report, therefore the results of the HIV Futures II study for this population have been used for comparison.

Twenty-three Aboriginal and Torres Strait Islander people who were HIV positive completed the HIV Futures II Survey nationally in 1999 (Willis et al 2002). Only one was from Western Australia. Ages ranged from 30 to 59, with an average of 37.9 years. Eighteen were male and four were female (one did not identify their sex). Ten of the males cited homosexual or bisexual contact as the likely mode of transmission, while three indicated risk through combined homosexual contact and injecting drug use. Seven people, including the four female respondents, cited heterosexual contact as the likely mode of transmission. Three people did not indicate the likely mode of transmission. Four of the 23 lived in a rural area.

Figures 1 to 3 below show the differences in age, sex and rural/metropolitan residence between the current research population, the WA respondents to the HIV Futures 3 Survey and the Aboriginal and Torres Strait Islander respondents to the HIV Futures II Survey.

Figure 1: Sex distribution of HIV research populations.

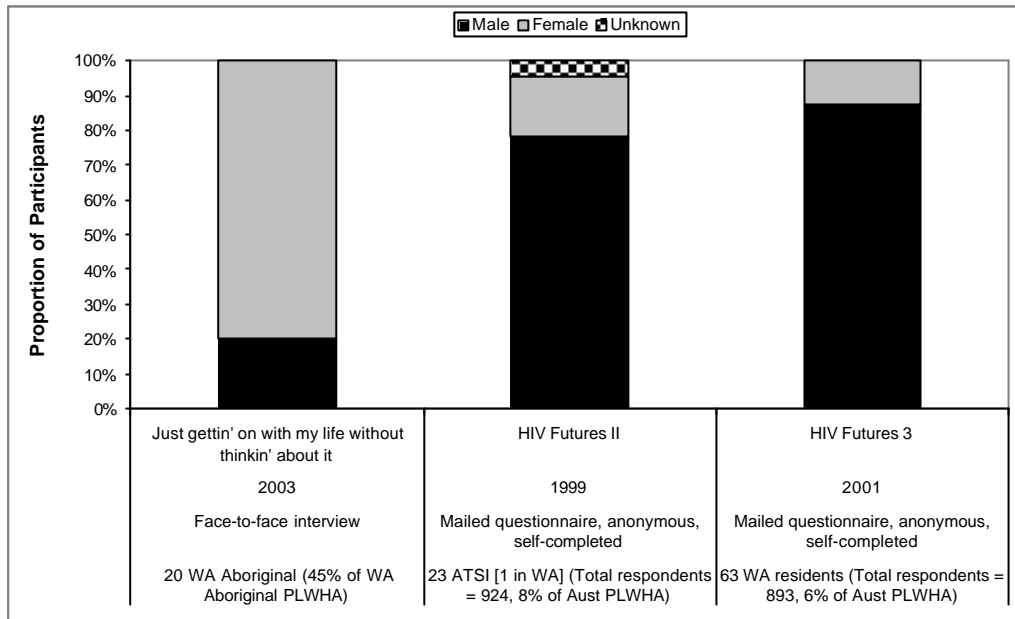


Figure 2: Mode of transmission of HIV research populations.

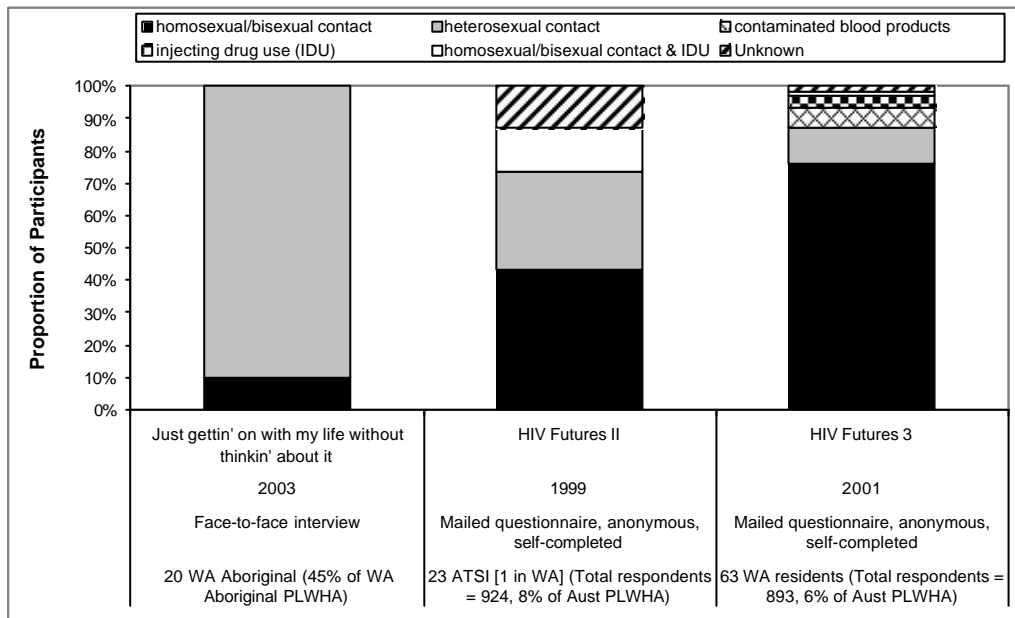
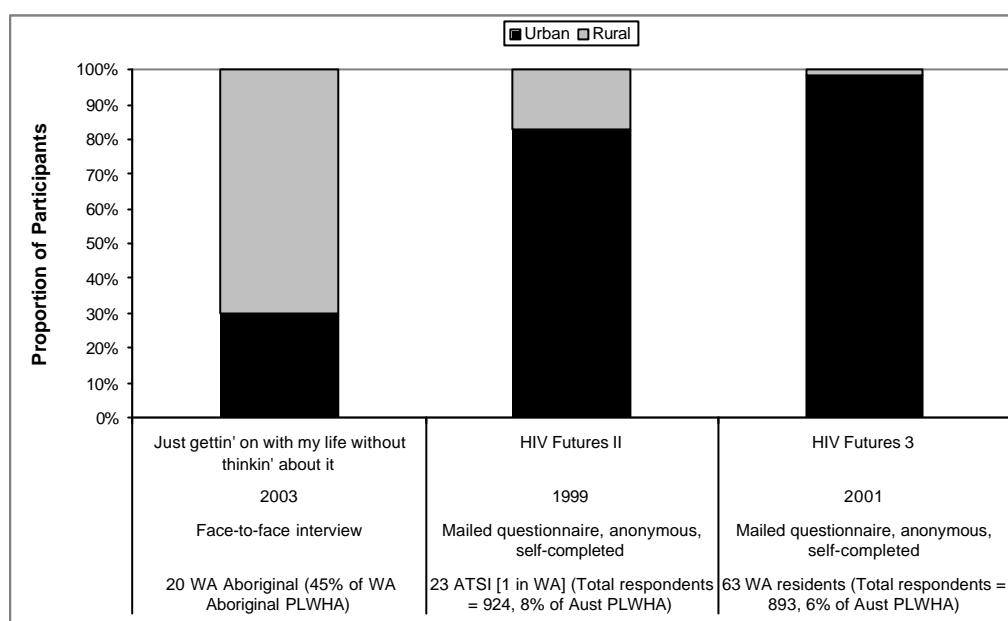


Figure 3: Rural /Urban distribution of HIV research populations.



The current study has a much higher proportion of females, a higher proportion of cases associated with heterosexual contact, and a higher proportion of rural residents. Participants are significantly younger than the Western Australian respondents to the HIV Futures 3 Survey, and the Aboriginal and Torres Strait Islander people who responded to the HIV Futures II Survey. The Aboriginal population living with HIV in Western Australia has been largely invisible.

The current study provides a unique insight into HIV infection in Aboriginal people in Australia, particularly women, and people who live in remote areas. The generally positive approach to living with HIV is a tribute to the individuals themselves and their service providers.

(b) Experience of living with HIV

Of the twenty participants, only one expected a positive diagnosis. For the remainder, there was generally a low perception of risk of being infected with HIV. Only six had a reasonable knowledge of modes of transmission of HIV prior to diagnosis. Alcohol was a significant factor in risky sexual behaviour.

There were common patterns apparent in participants' descriptions of living with HIV. Early reactions included shock, shame, fear of dying, feeling stigmatised, depression, increased substance use and renewal of family ties with social withdrawal from the wider community. This was followed in varying degrees by acceptance, and by HIV becoming a less dominant factor in day-to-day living.

Some participants were still coming to terms with an HIV diagnosis, while others had been living with HIV for several years and had accepted their condition. Participants spoke of trying to maintain good health by improving their diets and decreasing their substance use, then effectively ignoring their condition except when they were reminded of it by medical appointments or having to take medications.

The psychological or emotional impact of living with HIV appeared to be greater than the physiological effects for the research participants. For those who had been living with HIV for several years and who were able and willing to tell their story, early fears of dying had not eventuated.

Even in the most recently diagnosed participants, HIV was initially regarded as a death sentence. The perception was that HIV is swiftly followed by AIDS, then death, in a “Grim Reaper” type scenario. This reflects the fact that much public awareness of HIV occurred in the 1980s when treatments were not available. There is a need for accurate and up-to-date information regarding living with HIV, rather than dying of AIDS. The rural health service in the regional area of special need has developed expertise in HIV health promotion and prevention initiatives of this type.

Social support and disclosure

The greatest sources of social support and in coping with a positive diagnosis were partners, family members and friends. Health care providers were important sources of social support for many participants, particularly those who had not disclosed their positive status to anyone, or those who had disclosed to only a small number of people. Two participants reported that they were advised of their HIV diagnosis in the presence of a close family member or partner, who subsequently disclosed to other family or community members without permission. A total of five participants reported unwanted disclosure by family members, former partners or friends, while two believed that unwanted disclosure had occurred by Aboriginal Medical Services they had attended.

The lack of privacy and difficulty in keeping secrets in the Aboriginal community was also an issue for participants.

One participant reported that he wished he had stressed when disclosing that the information was confidential, and had not just taken it for granted that it would be treated as such.

Although disclosure of HIV status to family or friends has many benefits, particularly in increasing social support and in helping Aboriginal people to cope with an HIV diagnosis, unwanted disclosure can cause distress and discrimination.

Discrimination

Thirteen of the twenty research participants had experienced discrimination by family, friends or community members as a result of their HIV status in relation to people being reluctant to share eating and drinking utensils or keeping their distance through fear of being infected (5) or of being insulted or called names (8). Being called an “A.C.C.” was the most hurtful of insults. This was confirmed when the Senior Research Officer attended an Aboriginal women’s retreat to discuss the research and to obtain feedback on the research findings, when the women talked about the feelings of shame, stigma and hurt this caused them.

Changing discriminatory attitudes can be difficult. A number of participants recommended having positive speakers, particularly Aboriginal positive speakers to educate the Aboriginal community about living with HIV. Face-to-face community talks given by positive speakers are more likely to promote empathy and allow people to gain an understanding of living with HIV from the point of view of an infected person telling their own story.

Recommendation 1

Establish an HIV positive Aboriginal speaker’s program. This will require the provision of training in peer support and public speaking to Aboriginal people who are HIV positive. The aims of the program include making HIV visible to Aboriginal people, providing community education and leadership about HIV and promoting respect and empathy for those who are HIV positive.

Although discrimination occurred, and for a small number of people this was pervasive and ongoing, all participants had social support from family and friends. When a cluster of HIV positive infections in Aboriginal people was diagnosed in Western Australia in the mid 1990s, health providers were concerned that individuals might be rejected by their families or their communities. There was anecdotal evidence that this had occurred in a small number of cases, however, none of the research participants reported this.

Two participants reported discrimination by health providers in relation to their HIV status. One experienced discrimination while attending the dental hospital. The other experienced discrimination by hospital workers and within the prison system in the 1990s due to the previous policy of segregation of prisoners who were HIV positive in a special unit. This no longer occurs. The participant who was interviewed while in prison did not report any current discrimination from this source.

Prior to the research, there were anecdotal reports that discrimination by health providers had occurred in some areas, therefore it was surprising that only two participants reported this. One explanation offered by Aboriginal members of the Project Steering Committee and the Reference Group was that discrimination towards Aboriginal people is so pervasive, that participants may not have perceived this as being related to their HIV status, but part of the day-to-day experience of Aboriginal life.

Economic impact of living with HIV

Only one of the twenty research participants was employed and this was on a Community Development Employment Project, where income is similar to unemployment benefits. One was dependent on an employed partner who earned a minimal wage. The remaining eighteen (90%) reported that their main source of income was a government benefit, pension or social security payment.

Two metropolitan participants (10%) reported that their incomes had dropped because they had to stop work due to their HIV infection, or to the side effects of antiretroviral medication.

All twenty participants were on very limited incomes, although eighteen (90%) reported that living with HIV had not had an adverse effect on their financial situation or their accommodation. Eight (40%) stated that they had sufficient income to meet basic needs, while twelve (60%) did not. Research participants (and other Western Australian people who are HIV positive) are eligible to receive free antiretroviral medication, which differs from other states where a co-payment is required. Participants also accessed free medical services.

By comparison, 43% of the sixty-three Western Australian respondents to the HIV Futures 3 Survey were employed, with 60% of those working full-time and 40% part-time (Grierson & Misson 2002). Fifty per cent of respondents reported that their main source of income was a government benefit, pension or social security payment, 40% reported that a salary was their main source of income. Twenty-eight per cent of Western Australian respondents were living below the poverty line. Twenty-two per cent found it very difficult to meet the cost of food and 28% found it very difficult to meet the cost of utilities such as gas, electricity and telephones.

Six of the twenty-three Aboriginal and Torres Strait Islander respondents to the HIV Futures II Survey were employed (Willis et al. 2002). Thirteen were dependent on a government benefit or pension, eight reported their main source of income was a salary and one reported superannuation/savings/annuity, as the main source of income. Six were living below the poverty line. Twelve had difficulty in meeting the cost of food and sixteen had difficulty in meeting the cost of utilities. Nine had difficulty in meeting the costs of HIV/AIDS medications.

Research participants in the current study experienced higher levels of unemployment and a higher percentage were dependent on government benefits, pensions and social security payments than both the Western Australian respondents and the Aboriginal and Torres Strait Islander respondents to the HIV Futures 3 Survey. Despite living on very limited incomes, participants did not believe that HIV had had an adverse effect on their incomes, with the exception of the two participants who had ceased employment. The co-payment costs of antiretroviral medications place an extra burden on people who are HIV positive, therefore having access to free medication and medical treatment is helpful.

Accommodation

One rural participant reported that although he was entitled to Homeswest rental accommodation and a Disability Allowance, he had been unable to access either because he did not wish to disclose his HIV status to local Homeswest or Centrelink staff. It would be easier for rural people to access these services if there was a nominated staff member in their Perth offices to process applications. This would also limit access to confidential information.

Recommendation 2

Introduce, through consultation with Homeswest and Centrelink in Perth, a mechanism by which processing of applications for accommodation and Disability Allowances can be done centrally, so that individuals in rural areas are not required to disclose their HIV status to local staff.

Six of the twenty research participants were tenants of rented Homeswest or Aboriginal Corporation accommodation and all had family members residing with them, which included children, partners, siblings or other members of the extended family. One of the six was in prison at the time of interview, but had been allocated Homeswest housing prior to release and a female relative was planning to reside with her. Eleven participants resided with relatives including in-laws, two were temporarily living in hostel accommodation and one shared private rental accommodation with friends. None owned or were purchasing their own homes.

By comparison, 47% of the sixty-three HIV Futures 3 Survey respondents from Western Australia owned or were purchasing their own home, 32% lived in private rental accommodation, 13% lived in public rental accommodation, while 8% lived rent free. Thirty-two per cent lived alone, 40% lived with a sexual partner, 11% lived with friends or housemates, 15% lived with dependent children and 10% lived with other family members (Grierson & Misson 2002).

It was noted that Aboriginal and Torres Strait Islander respondents to the HIV Futures II Survey had less residential stability than other respondents to the survey, in terms of length of residence at their current address (Willis et al. 2002). It was also noted that seventeen of the twenty-two who gave information regarding postcodes had moved since diagnosis and perhaps against expectations, movement was away from the metropolitan epicentres of the HIV epidemic in Australia. No information was given regarding types of accommodation.

Eighteen of the twenty research participants in the current study had travelled to other locations since diagnosis. This ranged from short visits to other communities, towns, cities or another state to visit family members, to attend conferences or to fulfil employment or study requirements, to relocation from one rural area to another or between rural and urban areas. The two participants who had not travelled to other locations had been diagnosed less than one year at the time of interview and both had been living on the streets when diagnosed. While both of them remained in metropolitan areas after diagnosis, one had returned to live in his mother's home and the other had moved to a hostel.

None of the research participants reported relocating for the purposes of accessing HIV health care.

Social impact of living with HIV

Eleven of the twenty research participants believed that their HIV status was a barrier to forming new relationships. Barriers included fear of rejection, difficulty in persuading a new partner to use condoms, worry about the consequences of disclosing their HIV status or being identified as such by requesting condom use, and being referred to the Case Management Program for knowingly exposing a sexual partner to infection.

Only six of the sixteen female research participants had a regular relationship. One had a partner who was known to be HIV positive. The other partners had either repeatedly tested negative, or their status was unknown. None of the couples were using condoms, so there is potential for further transmission.

None of the four males had a regular relationship at the time of interview. Of the two gay male participants, one did not believe that his HIV status had created barriers in meeting new partners, while the other reported that although he did meet new partners, he had restricted his socialising and tended to spend more time with existing friends since diagnosis.

The remaining two males and one of the female participants reported that the relationships they had been involved in had ended with their HIV diagnosis. One of the males thought it would be easier to form a new relationship with a woman who was also HIV positive.

One of the female participants who was not in a regular relationship had recently separated from her de facto husband, who was also HIV positive. She acknowledged barriers to forming a new relationship and was contemplating a reconciliation.

Four of the six females who had a regular relationship reported that they were happy with their relationships. One of the four had only recently formed a new relationship after several years of being single.

Of the two females in a regular relationship who indicated that they were unhappy, one expressed a wish to be single again, while the other remained in the relationship because she had a strong desire to have a child.

Four of the ten females who did not have a regular relationship stated that they did not wish to have one.

Although many of the research participants claimed that their lives had not been changed too much by their HIV status, the majority of them are not involved in ongoing relationships and acknowledged that their positive status creates considerable barriers in engaging in new sexual relationships. Some appear to be resigned to this state of affairs, and display sadness at the lack of a close sexual relationship.

(c) Fertility

Only one of the four male participants had children, all born prior to his HIV diagnosis. He was single at the time of interview and had not seen his children for some time. Another male participant expressed a desire to have children, although he too was single at the time of interview.

Only three of the sixteen females had no children at the time of interview and one was past childbearing age. The two others expressed a desire to have children, although one of these was single at the time of interview and had little expectation of fulfilling this desire.

Nine of the sixteen females had children prior to diagnosis. Four of the nine were pregnant again at the time of HIV diagnosis. All but one of the four had successful pregnancies and there were four subsequent successful pregnancies in this group of nine, resulting in seven live births. One of the women who was pregnant at the time of diagnosis in the mid 1990s, was advised to have an immediate termination and tubal ligation. She followed this advice and has regretted the loss of her fertility since then. She reported that she has inquired about having the tubal ligation reversed, however she would have to pay the cost of this privately. With her very limited income, it is unlikely that she will be able to save the amount required for the operation. Abortion and tubal ligation are no longer recommended as a matter of course to women who are HIV positive, as they often were in the early years of the epidemic (Strebel 1995; Friend 1992).

Four of the sixteen female participants had had their first child since diagnosis. One was expecting her second child and another her third, at the time of interview.

In summary, nine of the sixteen female participants have had twelve live births since diagnosis, with two of the nine giving birth to more than one child. Eight of the nine lived in rural or remote areas when pregnant and all gave birth at King Edward Memorial Hospital for Women in Perth. Only one had a caesarean section, due to an unrelated health problem which existed prior to HIV diagnosis. All nine women were prescribed antiretroviral medications during pregnancy and their babies were prescribed them for six weeks after birth. All of the children were bottle-fed and none were HIV positive. Only two of the nine women expressed regret at being unable to breastfeed their babies. Average age at HIV diagnosis for female participants was 24.8 years. The four women who had had their first pregnancy since diagnosis were seventeen years or younger when first informed of their diagnosis. The youth of some of the female participants at diagnosis demonstrates early onset of unprotected sexual activity.

In Western Australia a multidisciplinary monitoring and support team comprising doctors, nurses and health workers from Royal Perth Hospital, King Edward Memorial Hospital, Princess Margaret Hospital, Fremantle Hospital and the Department of Health Western Australia, manages all pregnancies in HIV positive women (McKimmie 2003).

In 2002, a retrospective observational study on all pregnancies in HIV infected women who had been managed by the team was carried out (Cain et al. 2002). Between 1991 and July 2002, 32 pregnancies in 26 HIV positive women were managed by the team, resulting in 33 live births (including one set of twins). Twelve (44%) of the 26 HIV positive women were Aboriginal. Treatment included antiretroviral drug therapy during pregnancy for the mothers and after birth for the babies. None of the babies were breastfed and all were tested for HIV at least twice to ensure they were free of infection. Only one of the 33 children had acquired HIV infection and this was in 1991. Several older children had been found to be HIV positive when they were tested after their mothers had been diagnosed, however those pregnancies had not been monitored by the team. The study demonstrated that it was possible to achieve a very low rate of perinatal infection without requiring elective caesarean section, using a multidisciplinary approach to team management.

In Western Australia, rural women who are HIV positive are advised to relocate to Perth four weeks prior to delivery at King Edward Memorial Hospital. Five of the eight rural research participants reported that this posed no problem, however three reported problems which included loneliness, worrying about home or about their children being left in the care of relatives, and homesickness. One participant, who was a teenager when pregnant, had initially refused to fly to Perth for the delivery of her first child, because she was expected to travel alone and she wanted her partner to accompany her. She consented to go only when arrangements were made for her partner to fly with her.

In rural areas some distance from Perth, HIV positive women are generally booked on a commercial flight to the city. Partners or other family support persons may have to make their own travel arrangements, although rural health services or the Social Work Department of Royal Perth Hospital may provide assistance with transport and accommodation expenses. Relocating from a rural or remote community to the city for four weeks to give birth can be an isolating and alienating experience for some women (Portsmouth & Bennell 1997). It can be particularly daunting for young women having their first child.

Recommendation 3

Ensure social support for HIV positive Aboriginal women who are relocated for antenatal care and delivery. Where women are transferred to Perth prior to confinement, assistance with transport and accommodation costs is likely to be required for a partner or close relative to accompany them.

In the regional area of special need, a core of expertise has been developed in managing the health of Aboriginal people who are HIV positive, including the day-to-day management and monitoring of pregnancies. An evaluation of the program deemed it to be a successful, well run and well resourced program (Pitman 2001). It was noted that the willingness of pregnant women to comply with the antiretroviral medication regime was a reflection of the effectiveness of the program and their positive relationship to the local Department of Health staff.

The Senior Research Officer visited an Aboriginal Positive Women's Retreat in the final stages of the study to obtain feedback regarding the research findings. Two of the issues the women raised related to bottle feeding and the need to relocate to Perth to give birth. The combination of both these factors raised suspicions in their community, which could identify Aboriginal mothers as HIV positive. They perceived this as a problem in terms of confidentiality of HIV status in communities where there is a high level of awareness of HIV.

(d) Health care & access to HIV information and support services

Experience of health and wellbeing

None of the participants reported any major illnesses resulting from HIV. The most common health problems reported were depression/sadness (9) fatigue (8) and stress/anxiety (4). Other health problems reported were susceptibility to colds and flu, gynaecological problems, boils or abscesses, memory loss, mood swings/anger, fear of dying, sleeping difficulties, sweats, weight loss and loss of appetite.

The good health status of participants is likely to represent a healthy volunteer effect as individuals who are ill are less likely to participate in a research interview. Indeed, two people who were considering participating in the research were admitted to hospital and their health providers considered that they were too ill to be interviewed. Another reason may have been that some participants who had recovered from illnesses and were feeling quite well at the time of interview, tended to focus on their health as it was that day. They did not refer back to previous episodes of illness when asked to describe how HIV had affected their health. None of the participants reported an AIDS diagnosis, although they were not specifically asked about this.

The most common strategies adopted to maintain health and wellbeing were reducing or ceasing substance use (14), improving diet (13) and exercise/walking (4). Other strategies included maintaining normal activities, participating in sport or recreational activities, smoking cannabis, seeking prompt medical treatment when sick and reducing stress. None of the participants reported any use of complementary therapies or bush medicines.

Medications

Nine of the participants, two males and seven females, were not taking antiretroviral medications at the time of interview. Four of the nine had previously taken antiretrovirals during pregnancy only, two had been diagnosed for less than a year and had never been prescribed them, one had previously been taken off medications because she did not take them regularly and two had ceased medications due to side effects such as vomiting, feeling ill, headaches and dizziness.

Eleven of the participants, two males and nine females, were taking antiretrovirals at the time of interview. Six reported no problems with current medications, while five reported side effects which included panic/anxiety attacks, short-term memory loss, mild lipodystrophy, dizziness, headaches, insomnia and weight gain. Five had had one or two changes of antiretroviral combinations previously due to side effects which included weight gain, hair loss, insomnia and gastric upset.

One female participant reported feeling stigmatised and unattractive due to the side effects of previous medications, which included weight gain and hair loss.

Other problems with medication included forgetting to take afternoon or evening doses of medications, particularly when not at home; having to hide medications and missing doses of medication when drinking alcohol. Two participants reported that they 'doubled-up' their medications if they missed dosages through either forgetting them or because they were drinking.

Alcohol

Alcohol use featured in the stories of many of the participants, and most had reduced their alcohol intake to improve their health. Many acknowledged that alcohol had been an important factor in their engaging in risky sex, contributing to the events that led to their exposure to HIV infection. They were also aware that heavy alcohol use could have adverse effects upon their health and affect the progression of HIV infection. Some had stopped drinking completely, often after a period of heavy use in the period when they came to terms with their diagnosis. Those who continued to use alcohol often altered their treatment regime to try to reduce the harm from their alcohol consumption, for example by delaying doses and then adjusting for missed or delayed doses. It is not known to what extent continued alcohol consumption results in impaired adherence with treatment regimens that contributes to a poorer outcome or increases the risk of antiretroviral resistance, but this is an issue worthy of further study. What is clear is that those interviewed were aware of the potential adverse effects from mixing alcohol with their treatments, and like other HIV positive people, make risk assessments and modifications to their lives and treatments to reduce adverse effects.

Health care

Due to the mobility of research participants, many had accessed HIV health care from a variety of sources (see Appendix 3 for a detailed description of HIV health services in WA). When residing in metropolitan areas, most participants accessed specialist HIV outpatient clinics at Royal Perth Hospital or Fremantle Hospital. One metropolitan man accessed an HIV specialist GP and the Western Australian AIDS Council Clinic. For general medical services, other metropolitan participants accessed Aboriginal Medical Services or General Practitioners.

Participants living in the regional area of special need accessed HIV care and ongoing general health care from a small multidisciplinary team at the regional health service, which was visited by HIV specialists every three months.

Participants residing in other rural areas were assisted to travel to Perth approximately every three months to keep HIV specialist appointments at Royal Perth Hospital. Other health providers they accessed for general health care included General Practitioners, Community Health Nurses, Public Health Nurses, Aboriginal Medical Services, Prison Health Services and remote area clinics.

All participants had access to good quality HIV health care and there was a high level of satisfaction with the health services provided. The sample may be biased in that the majority of research participants were recruited via health providers (15), with three referrals from the Case Management Program and two from the Western Australian AIDS Council. Those who have a good relationship with, and access to health and service providers were more likely to volunteer for interview.

The HIV health services that were most highly regarded provided holistic services which met participants' emotional, social and welfare needs as well as their clinical needs. There was a distinct preference for 'mainstream' or small-scale state health services, which also employed a small number of trusted Aboriginal Health Workers, such as that provided in the regional area of special need. Health services that provided an informal, comfortable environment, transport, continuity, privacy, gender and culturally appropriate programs and services with a low staff turnover were more conducive to building trusting relationships with participants. Confidentiality was of the utmost importance.

While privacy and confidentiality are necessary in all health care fields, it is a particularly salient issue in the sexual health field, which involves sensitive issues, stigmatised conditions and marginalised populations (Plummer 2003). Confidentiality was a persistent and recurring theme strongly influencing participants' views of health services. Individuals want to be able to access services anonymously and privately, particularly sexual health services.

Generally speaking, individuals prefer to consult a doctor or nurse who is not part of their social network, a stranger, or someone whom they see only in the formal doctor/patient role, particularly when seeking sexual health care. To have an examination by a person they meet on social or business occasions is a situation that can be embarrassing and may reveal intimate confidential details that they would prefer not to discuss with a friend or colleague. In this sense, the service feels neither confidential nor private. This is a particular issue in rural areas, where people in the local community are known to each other and often share social networks. Local health professionals are part of the social fabric of everyday life and this may create barriers in accessing health care.

When one participant said "it's not confidential," in relation to the rural health service she attended, she was not referring to breaches of confidentiality, rather that too many people knew of her HIV status in their legitimate roles as health providers in her rural community, due to recent staff changes. She was also missing the Aboriginal Health Worker who had provided her with support, counselling and ongoing care since diagnosis, but who no longer worked there.

Privacy and confidentiality issues are compounded for Aboriginal people in urban as well as rural areas, due to their extensive social and kin networks. Family members or friends may be employed at Aboriginal Medical Services, or at mainstream health services. Aboriginal people who are HIV positive and who do not wish their status to become known to other members of their social and kin networks, will avoid those services where this is a possibility.

Only two participants reported breaches or suspected breaches of confidentiality by staff of Aboriginal Medical Services, yet many of the participants perceived that there is a lack of confidentiality. "Confidentiality" is more about privacy and invisibility than actual breaches of confidentiality. Participants were very concerned about the number of people in the community who may become aware of their HIV status. It was clear that they preferred to use a service which had a small number of staff and few staff changes.

Outreach services can be problematic in small communities. For example, even if vehicles have private number plates, health professionals, particularly Aboriginal Health Workers, are known in the community and their vehicles are easily identified. Health professionals with sexual health responsibilities have responded to this by blurring or widening their roles in an attempt to avoid identifying the clients with whom they work. Nevertheless, it is clear there is some ongoing anxiety for HIV positive clients that such camouflage could be unmasked.

One HIV specialist outpatient clinic received criticism related to the physical environment of the clinic, particularly the lack of confidentiality in the waiting area where patients were called out by name. The waiting area of the clinic was in an open area in a long corridor, with no windows. It was not perceived as a comfortable place for Aboriginal people. (Although not part of the research analysis, one of the non-Aboriginal HIV positive men who volunteered for a practice interview had similar criticisms of the clinic, stating that it was "not a conducive environment" and that patients are "herded along like cattle, along with everybody else...there's very little confidentiality.") Waiting areas in clinics are potential sources of anxiety for clients, because their HIV status can become known or suspected by others in the waiting area. If they are called by name at reception, then their identity is also known and their confidentiality is inadvertently breached.

Large institutional health services with an emphasis on clinical care, treatments and medications can be intimidating to Aboriginal people. Participants expressed a preference for small, Aboriginal-friendly, community-based services, which invite and support patient input into care, where staff are respectful and show understanding of the realities of Aboriginal people's lives.

The research findings have been heavily influenced by participants from the regional area of special need, which has a dedicated holistic health care service to support them and provide advocacy for them. It is essential that this level of support continues and that similar services are developed in the metropolitan area, which provide holistic care and meet the needs of Aboriginal people who are HIV positive.

During the period in which the research interviews were conducted, there was increasing recognition by the Department of Health that support services were needed in the metropolitan area. As a result, the Ruah Health Support Team commenced a mobile 'inreach' service in the Perth and Fremantle areas, offering psychosocial support to people living with HIV and experiencing chaotic lifestyles. The holistic, client-centred service offered by Ruah is very much supported by the findings of this research. This service however is only available to a small number of people who are experiencing problems with homelessness, mental health issues, substance use and other significant social disadvantage.

There was a lack of recruitment for the current research from the major outpatient HIV specialist clinic, with those participants who access this clinic for treatment being recruited to the research by the Case Management Program, the Western Australian AIDS Council and an Aboriginal Health Worker. Participants felt there was a strong emphasis on treatment rather than holistic care at this clinic. There appeared to be concerns with upsetting patients and losing them to treatment by referring them to "outsiders".

Recommendation 4

Broker changes to the clinical service arrangements provided by one major HIV specialist outpatient clinic based upon the feedback of Aboriginal patients. A priority is to shift the emphasis from assessing the patient's need and response to drug treatments, to managing the whole patient in the context of their personal, social and community life. Treatment services must provide a culturally secure, confidential and holistic service that meets patients' needs in a non-alienating environment.

Participants' suggestions for improvements to health services

The majority of suggestions for improvement to health services related to accessing HIV information and the social and cultural aspects of living with HIV, rather than the medical or clinical aspects. Twelve participants were satisfied with the HIV health services they were receiving and did not offer any suggestions for improvement. Eight suggested the following improvements:

Metropolitan participants' suggestions included the provision of more HIV information; holistic, user friendly, gender and culturally appropriate services; outreach services; greater social support by arranging social outings and camps for groups of people who are HIV positive (not restricted to Aboriginal people) and designing HIV treatments and medications around the lifestyles, diet and alcohol intake of Aboriginal people.

Rural participants' suggestions included the provision of a hostel in Perth with a counsellor where rural people could stay while attending medical appointments; camps for Aboriginal people who are HIV positive; more access to respite accommodation; retention of staff; building a family house out of town in the regional area of special need, where people can go with their partners to relax, to be educated about HIV and to take part in structured activities.

One rural participant thought that HIV health services should be located in distant regions, such as the Kimberley, so that people there would not have to travel long distances for HIV specialist care, however, this participant was from a rural area much closer to Perth, and she herself expressed a preference for travelling away from her local area to attend Royal Perth Hospital HIV specialist clinic.

Although the social and information aspects of the above could more readily be provided by HIV/AIDS organisations rather than health services, metropolitan participants tended not to use HIV/AIDS organisations and consequently, they sought information and support from their health services.

HIV Information and support services

There are two HIV/AIDS organisations in Western Australia which provide information and support services: the Western Australian AIDS Council and AIDS Pastoral Care, both of which are located in Perth. Although the centralisation of services is a barrier to access for rural residents, few metropolitan research participants accessed those services either.

None of the participants reported that they had accessed AIDS Pastoral Care for assistance or support.

Six participants, four metropolitan and two rural, had received assistance or support from WAAC, with five of them reporting contact on only one or two occasions. Only one participant, a gay male, reported ongoing contact with WAAC, where he worked as a volunteer providing peer support and public speaking services. He was also a member of the national Indigenous Positive Network, but at the time of interview, he reported that he had not met any other Aboriginal people in Western Australia who were HIV positive.

One female participant reported that having to enter an "AIDS Council" made her uneasy. Participants generally did not like the word "AIDS". They made frequent reference to the ignorance in the Aboriginal community between "HIV" and "AIDS" and made the distinction, "I haven't got AIDS, I got HIV."

In the regional area of special need, the rural health service provided HIV information and support services including Positive Retreats, in addition to ongoing clinical care via a small multidisciplinary team, which included a Case Management Officer and an Aboriginal Health Worker.

Three participants reported that they regularly received support, assistance and information from the Case Management Program in Perth.

Participants who accessed support services other than via their health providers, were more likely to receive these from generalist agencies in their local community.

One metropolitan participant received ongoing assistance with meals and support from a non-government community agency.

One rural participant received home help services locally in relation to a disability unrelated to her HIV infection. She also regularly accessed accommodation at a women's refuge/hostel in Perth and received assistance and support from the staff there when she attended HIV specialist appointments at Royal Perth Hospital.

When obtaining feedback regarding the research findings, one metropolitan participant reported that he and his current partner were now receiving ongoing outreach support and assistance from Ruah Health Support Team, and both spoke highly of the service provided. This included counselling, home visits, transport to and from clinic appointments and being taken on social outings.

Due to the lack of privacy, many Aboriginal people who are HIV positive do not take HIV information booklets or leaflets home with them, because possession of HIV information may raise suspicions in the community as to their HIV status. For nineteen of the twenty participants, their major sources of information regarding treatments, HIV management and living with HIV, were the health care professionals who provided ongoing health care. Twelve of the nineteen reported that they accessed information from the health service in the regional area of special need; four from Royal Perth Hospital; two from Fremantle Hospital; and one from a rural Registered Nurse.

The remaining participant accessed information regarding HIV management from an HIV specialist GP. For information regarding treatments and living with HIV, he accessed WAAC. He was the only participant who reported HIV/AIDS newspapers and magazines and gay press publications as regular sources of information.

Five participants named secondary sources of information, which included Royal Perth Hospital specialist outpatient clinic (2), Perth Case Management Program (2), and a GP (1).

Nine participants named other HIV positive people as sources of social support. Contact with positive people was largely informal, and occurred mainly with relatives or with people who lived in reasonably close proximity.

By comparison, 75% of the Western Australian respondents to the HIV Futures 3 Survey had direct contact with an HIV/AIDS related organisation. Of those, 71% received a newsletter, 61% were clients, 23% were volunteers, 11% were members and 10% were staff (Grierson & Misson 2002). Western Australian respondents were found to be significantly less likely than those from other states to be members of HIV/AIDS organisations and more likely to have used an HIV specialist at an outpatient clinic, a hospital social worker or counsellor and an AIDS organisation support worker than those from other states. They also received significantly less support from health care workers than those from other states. Ninety-five per cent of Western Australian respondents knew other people who were HIV positive; 28% spent no free time with them, 35% spent "a little" time, 29% spent "some" time, and 8% spent "a lot" of time with other people who were HIV positive.

Of the twenty-three Aboriginal and Torres Strait Islander respondents to the Futures II Survey, twenty reported some contact with HIV/AIDS organisations (Willis et al. 2002). They used them for treatment advice (15), social contact (11), peer support (11), counselling (9), pharmacy services (8), drug/alcohol treatment (6), library (5) and financial assistance and advice (5). The most commonly cited sources of information were doctors who specialise in HIV treatment. Compared to other respondents, Aboriginal and Torres Strait Islander people were more likely to seek information about treatments from their pharmacists, their partners/lovers, and their family and they were less likely to seek information from the Internet. Compared to other respondents, they were more likely to seek information regarding living with HIV/AIDS from their alternative therapists, their partners/lovers, their family, and a Treatments Officer at an HIV/AIDS organisation. Respondents spent “a little” time (8), “some” time (7), or “a lot” of time (6) with other people who were HIV positive.

Retreats

Retreats provided an opportunity for the current research participants to meet other people who were HIV positive, to obtain information regarding HIV/AIDS and the services available, and to participate in social and leisure activities. Ten female rural participants had met other people who were HIV positive through attendance at Aboriginal Positive Women’s Retreats in Perth, arranged by the health service in the regional area of special need. Four women reported that they did not have any further contact with those they had met, because they lived in other parts of the state and communication between them was too difficult.

Two metropolitan participants, one male and one female, had attended retreats arranged by WAAC, however they did not meet other Aboriginal people at those. Of the remaining eight participants, two did not know that retreats were available; three were either planning to attend, or considering attending a retreat; and three had been invited to attend retreats but had declined because they were worried that they might meet Aboriginal people who knew them.

Suggestions regarding future retreats were varied. Six women stated that they would like to attend “mixed” retreats, to meet women from different cultures. One of the males stated that he would prefer to meet Aboriginal men and women from his own linguistic group, while one of the females stated that she would not attend an Aboriginal retreat.

One rural participant commented that when a small group of women from her town left together to attend a retreat in Perth, others in the community gossiped and the potential existed for their HIV status to be identified. She suggested that it was better for only two people from her region to attend a retreat and to meet people from other parts of the state.

The need for formal networks and communication structures

Contact with other positive people has benefits in reducing isolation, sharing experiences, problem solving and providing education and peer support. A number of factors create barriers to the formation of an Aboriginal “positive community” in Western Australia. These included lack of privacy, lack of telephones, lack of a private postal address, distance, and the fear of being identified in the community as HIV positive. There is a lack of material resources that makes networking and communication difficult. In addition, HIV/AIDS organisations are not perceived as user-friendly places for Aboriginal people (AFAO 2002).

The Western Australian AIDS Council in Perth currently employs two Aboriginal staff. In the regional area of special need, there are at least two people who have the capacity and willingness to provide peer support to other Aboriginal people who are HIV positive, and who in fact do so, on an informal basis in their own communities. There is, however, no formal communication structure to facilitate contact with those in other parts of the state or to the national Indigenous Positive Network. With modern technology such as email, the Internet, teleconferencing and videoconferencing, setting up a formal structure that would enable communication links with other Aboriginal people who are HIV positive should be possible, even in remote areas. Perhaps a conference for Aboriginal people in Western Australia would start the ball rolling?

Recommendation 5

Establish communication structures to reduce social isolation, by enabling confidential and anonymous contact between Aboriginal people who are HIV positive.

Due to the invisibility of the HIV epidemic among Aboriginal people in Western Australia and their social and geographic isolation, the HIV Futures National Surveys do not reach this population. Ninety-nine per cent of HIV Futures 3 Western Australian respondents lived in Perth. There have been missed opportunities to survey this population because the distribution strategies have not reached them. A rethink of their approaches may be required to gain a more representative sample in future.

Participants’ suggestions for improvements to HIV services

With regard to improving services other than health services for Aboriginal people who are HIV positive, participants made the following suggestions: a hostel or other accommodation for the homeless and as a meeting place; retreats, outings, camps; a drop-in centre or outreach service; increased access to respite accommodation; and public transport to a rural Aboriginal community.

Recommendation 6

Facilitate a range of appropriate and user-friendly HIV/AIDS information and support services, including social activities, to Aboriginal people who are HIV positive, both in metropolitan and rural areas.

(e) Health promotion and education issues

Research participants' suggestions for future HIV education in Aboriginal communities included the following topics:

Comprehensive HIV education including modes of transmission; susceptibility to other infections due to impaired immune system; the replication of HIV cells in the blood; the physical, emotional and social effects of living with HIV; HIV and pregnancy; and the difference between HIV and AIDS. Other topics suggested included HIV prevalence in the Aboriginal community, and that all are at risk, not only gay males; the links between alcohol, violence and sexual health; information on how to cope with HIV; how to access confidential support; and injecting drug use.

Education to dispel the ignorance of modes of HIV transmission (e.g. you can't catch it from sharing plates, touching or hugging an infected person).

In the regional area of special need, Aboriginal and non-Aboriginal staff in the health promotion team have developed considerable expertise in designing and delivering local HIV education and prevention campaigns. Many participants from this region reported that adults are already well educated in this regard, however, a common theme identified from participants' responses was concern for young people who may be sexually active from an early age without being aware of the consequences of unprotected sex, namely sexually transmitted infections and early teen pregnancy. Similar concerns were expressed regarding injecting drug use in young people.

Participants suggested that education regarding safe sex and injecting drug use should be delivered at primary school level, well before young people become sexually active. Other suggestions included the provision of more youth recreational outlets, particularly those which promote Aboriginal culture and involve creative arts, where sexual health can be promoted and condoms distributed.

Available research shows that effective formal sexual health education develops both skills and knowledge through participatory, experiential programs which model and provide opportunities to practise communication, negotiation and refusal skills. Programs need to focus on particular behaviours, not simply on imparting information regarding HIV and sexually transmitted infections (Robin et al. 2004; Department of Human Services 2000). Key messages are to delay sexual debut, reduce the number of sexual partners and use condoms. Education should include discussion of alcohol and other substances in increasing risk-taking behaviour. Programs should target those most vulnerable and at risk and involve parent-child activities where possible.

There is a need for sustained education programs, rather than one-off efforts, for young people in both school and community settings and for the wider community. Programs should also be delivered outside school settings to reach those who do not attend school, or who are in juvenile detention centres.

Recommendation 7

Increase and sustain the delivery of quality, Aboriginal-friendly sexual health and blood borne-virus health promotion and prevention programs. Programs must acknowledge and cater to Aboriginal diversity and include a range of non-print media. Age-appropriate programs for youth should include substance use as a risk factor and should be delivered both within and outside of school settings.

Participants suggested the following as appropriate strategies for delivering HIV health promotion and education programs to Aboriginal communities:

- Community education meetings
- HIV positive Aboriginal speakers tell their stories at community meetings, in schools and on videotapes
- HIV health promotion and awareness theatre, plays and sketches that entertain the community
- Distribute Aboriginal information booklets like *HIV/AIDS and Us Mob* (Costello & Duffin 2003)
- Develop local programs in partnership with community elders that can then be directly used by elders in their own communities
- Provide and update posters, leaflets and pamphlets in remote area clinics and Aboriginal fringe communities in towns
- Aboriginal Health Workers and other health providers to regularly visit and talk to remote communities about HIV
- Television campaigns.

Two participants did not want HIV to be a continuing topic in their communities, as they did not want constant reminders of their HIV infection and they worried about others finding out their positive status.

Risk behaviour

Despite exposure to HIV education and prevention campaigns, many individuals continue to engage in risk-taking behaviour in the face of knowledge. With regard to sexual transmission, condom use is widely promoted, however there are many reasons why individuals do not use condoms, or use condoms inconsistently. One is the desire for pregnancy.

For young Aboriginal women, pregnancy is an initiation into womanhood and independence, and when contraception is used by young Aboriginal women in rural Western Australia, it is likely to be Depo Provera, a long-acting injectable contraceptive, rather than condoms (Greville 2002).

Ethnographic research on culture-specific barriers in preventing HIV transmission in Pitjantjatjara men of Australia's central desert region, found that there were "manifold" barriers to condom use in this population (Willis 2003). Some of the barriers related to men's ritual ceremonies and associations, circumcision and subincision.

Condoms may not be readily available, particularly in rural and remote communities in Western Australia. They may have to be accessed from a public area or the waiting room at a local clinic and not in private places where they can be obtained discreetly. "Condom trees" and "condom mail boxes" have been trialled in remote areas of the state where people congregate to drink and socialise, to improve access to and promote the use of condoms (Greville 2002).

A study of condom use in young heterosexual men in Canberra identified several themes in accounting for non-use of condoms, which included partner's use of oral contraceptives; decreased penile sensation; difficulty with use; interruption to the "heat of the moment"; low perception of risk; and reliance on notions of trust and monogamy (Flood 2003). Condoms were used primarily to prevent pregnancy rather than the transmission of sexually transmitted infections, however in long-term or regular relationships, young men, like young women, commonly relied on oral contraceptive pills. Trust and monogamy ruled out condom use in a regular relationship.

Many young women also believe that monogamy is a safe sex strategy and that notions of love, caring and fidelity are incompatible with condom use, which is seen as a sign of mistrust (Seal 1996). They are more likely to use condoms with casual partners or at the beginning of a regular relationship. Buying condoms, carrying them around or discussing them with their partner may imply that they are promiscuous.

A low level of condom use or inconsistent condom use may be due to a low level of perceived risk. A study of adolescent females at high risk for sexually transmitted infections in Connecticut found that research participants clearly underestimated their risk (Ethier et al 2003). There was no relationship between participants' perceived susceptibility and indicators of STI susceptibility, which included the experience of symptoms, having had multiple partners and unprotected sex.

Even when individuals are educated about HIV or other sexually transmitted infections, they may engage in unprotected penetrative sex because they do not believe they are at risk of being infected. Reasons for a lower level of perceived risk of HIV by Aboriginal women in a Darwin study included trusting their partner; believing that HIV is something that happens to other people; and the lack of reported cases of HIV in the local community (Roberts & Cahill 1997). HIV was perceived as a remote danger.

Women may have no control over condom use, or be powerless to negotiate safe sex (Lawless et al. 1996; Strebel 1995; Kippax et al. 1990), especially younger women who are particularly vulnerable to HIV infection (UNICEF/UNAIDS/WHO 2002b; Greville 2002).

The Western Australian AIDS Council is currently trialling a peer-based learning program for women aged 18–25 years in the Perth Metropolitan area due to concerns at the rising rates of sexually transmitted infections in this population in WA.

We are currently seeing rises of STIs in the community, which can increase the risk of HIV infection tenfold – therefore this is a unique opportunity for the WA AIDS Council to promote sexual health and negotiation skills among young women (Shanks 2004).

A study carried out to identify risk factors for sexually transmitted infections in a remote Aboriginal population in central Australia identified three strong predictors of incident sexually transmitted infections, which were age (15–29 years), substance use and a history of previous sexually transmitted infections (Miller et al. 2001). People aged 15 to 19 years and women with a history of regular petrol sniffing were found to be particularly vulnerable.

Substance use may lead to unprotected sex by lowering inhibitions or through intoxication. Lack of power to negotiate safe sex may be eroded further by alcohol and substance use in young men and women (Greville 2002). Those who exchange sex for alcohol and/or other drugs are more likely to engage in high-risk behaviour in meeting their needs, as are homeless people who may exchange sex for food, shelter and/or financial gain (Roberts & Cahill 1997).

During 2002 there were eleven notifications of HIV in Aboriginal people in Western Australia, ten of whom were resident in the metropolitan area. Heterosexual contact was the mode of transmission for all of these new cases (Giele 2003). Some of the new cases occurred in a connected group of homeless people whose lifestyles were characterised by binge drinking or other substance use and high-risk sexual behaviour, leading to fears of a mini-epidemic in this population.

In Aboriginal communities where there is high awareness of HIV and condom use has been heavily promoted, to suggest using a condom may be perceived by either partner as an admission or an accusation of positive HIV status (Greville 2002). Asking a partner to use condoms may also raise suspicions of infidelity. This creates barriers to condom use for both those who are vulnerable to infection and for those who are already infected. For some women, disclosure of positive HIV status to a new partner can result in violence. Fear of violence may lead to non-disclosure and reluctance to suggest condom use, resulting in unprotected sex.

Education and knowledge, the ability to negotiate safe sex, the availability of condoms and accurate perception of risk are factors which influence individuals' decisions regarding sexual behaviour between consenting partners. Victims of sexual assault have no such choices and are vulnerable to HIV and sexually transmitted infections.

There is no way that you're going to slip a condom on in the middle of getting raped, it's just not going to happen (Arabena 1999).

The death of a 15-year-old girl in an Aboriginal community in Perth in February 1999 raised allegations of unaddressed sexual abuse, which resulted in a government inquiry, commonly referred to as the "Gordon Inquiry", into the response by government agencies to complaints of family violence and child abuse in Aboriginal communities. The report from the inquiry found that:

Evidence and research provided to the Inquiry indicate that family violence and child abuse occur in Aboriginal communities at a rate that is much higher than that of non-Aboriginal communities. The statistics paint a frightening picture of what could only be termed an "epidemic" of family violence and child abuse in Aboriginal communities (Gordon et al. 2002:xxiii).

Although they were not specifically asked about sexual assault, two female research participants volunteered the information that they had been sexually abused as children.

Child sexual abuse is associated with early first use of intoxicants, early initiation into sexual activity and increased rates of partner change (Jarvis et al. 1998). In response to the Gordon Inquiry, an action plan has been implemented by the Western Australian State Government to address child abuse and family violence in Aboriginal communities (Government of Western Australia 2002).

With regard to the transmission of HIV by injecting drug use, health promotion and prevention campaigns have promoted the use of sterile injecting equipment through needle and syringe programs. Studies of Aboriginal people and injecting drug use have concluded that there is a high level of sharing of needles and equipment. A lack of culturally appropriate services; a perceived lack of confidentiality of some Aboriginal-focused services; shame and stigma attached to injecting drug use; lack of awareness of services; and inconvenient opening hours were identified as barriers to services in relation to injecting drug use (Holly & Shoobridge 2002; Gray et al. 2001; Larsen et al. 1999).

There was concern regarding injecting drug use and tattooing in prisons where there was no reliable access to clean equipment (Gray et al 2001; Read et al 2003). The higher rates of imprisonment of Aboriginal people compound the risk (Larsen et al 1999).

Some injecting drug users have a low perception of risk of HIV infection. Many Aboriginal participants in one study rated their own chances of infection as remote, and HIV was not viewed as a "real and present threat" (Larsen et al 1999).

There are many other factors contributing to risk-taking behaviour in Aboriginal society, which impact on health and welfare. These include poor health and life expectancy, poor socioeconomic circumstances, environmental factors and lack of access to services (Edwards & Madden 2001; Watson et al. 2001; Aboriginal and Torres Strait Islander Social Justice Commissioner 2003).

Aboriginal people, particularly those living in remote communities, do not have adequate housing, sanitation and sewerage systems, nor do they have reliable supplies of electricity or safe water. Aboriginal people spend more of their income on housing than non-Aboriginal people living in the same areas.

Risk behaviour in relation to HIV infection must be seen in the broader context in which Aboriginal people live their lives. Social and cultural inequality, ill-health and poverty all impact negatively on individuals and communities.

Health promotion and preventative education programs are required so that individuals can make informed decisions and choices regarding sexual behaviour and injecting drug use. However, education alone is insufficient for the reduction in high risk behaviour. Individuals need to have the ability to negotiate safe sex and to have the knowledge and skills to accurately recognise their susceptibility to HIV and other sexually transmitted infections. The socioeconomic circumstances underlying poor health in general, and sexual health in particular need to be addressed.

Sexually transmitted infections in the WA Aboriginal population

There are major differences in the rates of sexually transmitted infections between Aboriginal and non-Aboriginal populations in Western Australia, with much higher rates in the Aboriginal population (Wright 2004). In 2002, the rate ratio for gonorrhoea was 87:1, while for syphilis it was 283:1. The high rates of sexually transmitted infections have the potential to rapidly increase the transmission of HIV in the Aboriginal population of Western Australia.

In September 2003, a Sexual Health Summit was convened in Perth to discuss the implications and impacts of the high rates of sexually transmitted infections in Western Australian Aboriginal communities and to develop partnership approaches in taking action to reduce them (Department of Health WA 2003).

Recommendation 8

Ensure that sexual health and blood-borne virus program development and delivery are supported by carefully selected, skilled, sexual health educators. It is imperative that high priority is given to ongoing, quality training of Aboriginal Health Workers, Health Promotion Officers and Youth Workers in sexual health.

6. CONCLUDING COMMENTS

The data presented here provided us with insight into the experiences of twenty Aboriginal people in Western Australia who are HIV positive and has enabled them to record their experiences for a wider audience. We hope that the information collected can be used to increase the understanding of the ways in which health providers and HIV/AIDS organisations can more effectively respond to HIV in the Aboriginal population of Western Australia, through education, treatments, health promotion and prevention, information and support services. We also hope that it will improve the quality of life for Aboriginal people who are HIV positive and stimulate further discussion and research into HIV in this population.

7. APPENDICES

Appendix 1: Epidemiology

Global HIV Epidemic

At the end of 2002, there were an estimated 42 million people worldwide living with HIV/AIDS. Five million people were newly infected with HIV in 2002 and 3.1 million died of AIDS. Patterns, rates and modes of transmission varied widely, with the most devastating impact of the pandemic occurring in Sub-Saharan Africa, where an estimated 29.4 million people were living with HIV/AIDS at the end of 2002. In that region, heterosexual contact was the main mode of transmission. In Eastern Europe and Central Asia, where 1.2 million people were living with HIV/AIDS at the end of 2002, the main mode of transmission was by injecting drug use, while in North America, with 980,000 cases, modes of transmission included men who have sex with men, injecting drug use and heterosexual contact (UNICEF/UNAIDS/WHO 2002a). Worldwide, more than half of those newly infected with HIV were people between the ages of fifteen and twenty-four years (UNICEF/UNAIDS/WHO 2002b).

The HIV Epidemic in Australia

General population

From the time the first Australian AIDS case was reported in 1981 until the end of 2002, a total of 22,548 people were diagnosed with HIV in Australia. Of these, 9,018 had been diagnosed with AIDS and 6,258 people had died. The main mode of transmission was men who have sex with men (77.4%) followed by heterosexual contact (11%). Transmission via injecting drug use remained low at 4.4% (NCHECR, 2003b).

The peak in diagnoses in Australia occurred in 1985, with over 2,500 HIV cases notified that year, followed by a substantial decline (Atthowe et al. 2003). This decline initially plateaued and in 2002 there was an increase in HIV notifications in three states compared to the previous year: New South Wales rose by 10%, Queensland by 20% and Victoria by 7% (Langdon 2003; AFAO 2003).

Aboriginal population

Aboriginal people were under-represented in Australian HIV/AIDS statistics prior to 1995. Many states and territories did not systematically record Aboriginal status in the notification of data (Neilsen & Hill 1993; Lee & Moore 1998; NCHECR 2002).

The first Aboriginal case of HIV/AIDS in Australia was reported in 1985 (Neilsen & Hill, 1993). Cumulatively, from 1985 to the end of 2002, a total of 180 Aboriginal Australians were diagnosed with HIV and 69 of

these had been diagnosed with AIDS (NCHECR 2003a). Overall, the rates of HIV and AIDS have been comparable for Aboriginal and non-Aboriginal people, although the age standardised rate of decline in incidence seen in the non-Aboriginal population has not been matched in the Aboriginal population (Atthowe et al. 2003; NCHECR 2002; Guthrie et al. 2000).

For the period 1983 to 2002, homosexual contact was the main mode of transmission for both Aboriginal and non-Aboriginal populations, however, the Aboriginal population has had a higher proportion of cases associated with heterosexual contact (30% versus 20%) and injecting drug use (16% versus 4%) and the proportion of females diagnosed is higher (27.8% versus 10.6%) (NCHECR 2002). In the Aboriginal population, the mean age for diagnosis of both HIV and AIDS is younger and there is a higher proportion of people with HIV living in rural areas (Guthrie et al. 2000).

HIV in Western Australia

General population WA

Since the first AIDS case was notified in Western Australia in 1983 to the end of 2002, cumulatively there have been 1,173 diagnoses of HIV infection in the state, 1,020 males and 147 females (sex not reported in six cases) (NCHECR, 2003b). There have been 449 AIDS diagnoses and 355 deaths notified in people with HIV (Giele 2003).

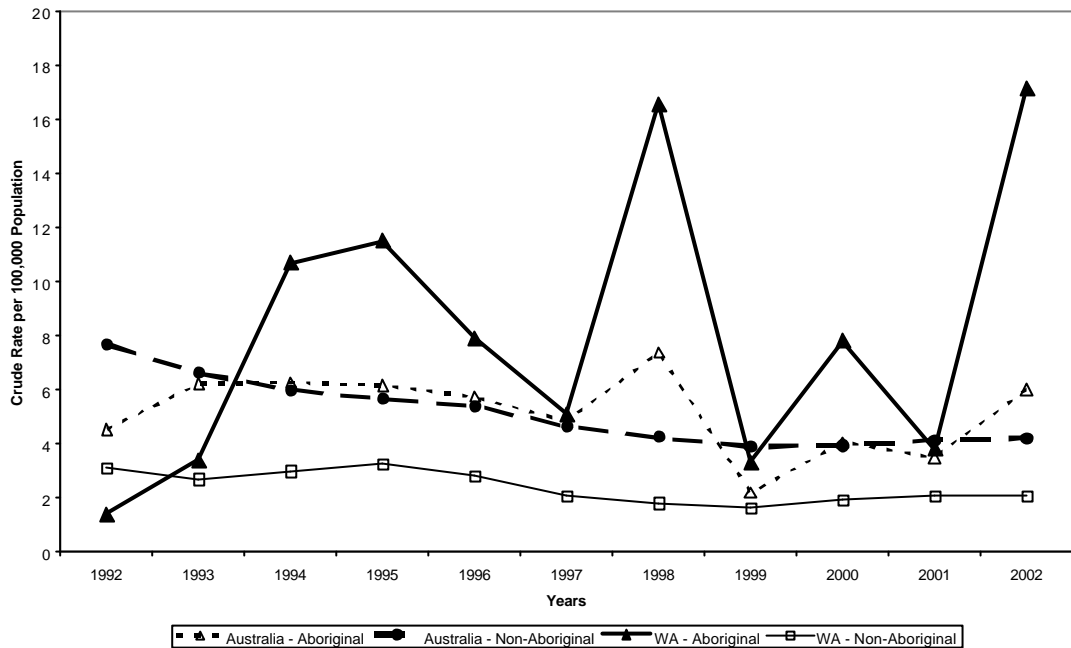
Aboriginal Population WA

The first Aboriginal case of HIV in Western Australia was notified in 1985. Cumulatively, from 1985 to the end of 2002, there were 60 new diagnoses of HIV in Aboriginal people in Western Australia, 22 AIDS notifications and 16 deaths. These 60 diagnoses comprise of one-third of the total of 180 new diagnoses of Aboriginal people who are HIV positive in Australia.

The 60 notifications comprised 28 males and 32 females ranging in age from two to 52 years, with a mean age at diagnosis of 30 years (median 31 years). Approximately half resided in the metropolitan area and half in rural areas of WA (Giele 2003).

Figure 4 shows the rates WA and national rates of HIV notification for Aboriginal and non-Aboriginal people. The non-Aboriginal rate of HIV infection in WA has consistently been well below the Australian rate. Since 1994, the rate for Aboriginal Western Australians has consistently exceeded that for non-Aboriginal people in WA. The number of infections in WA has had considerable influence on the rate of HIV infection among Aboriginal people nationally, and in the period 1996–2002, WA accounted for one-third of all Aboriginal HIV notifications.

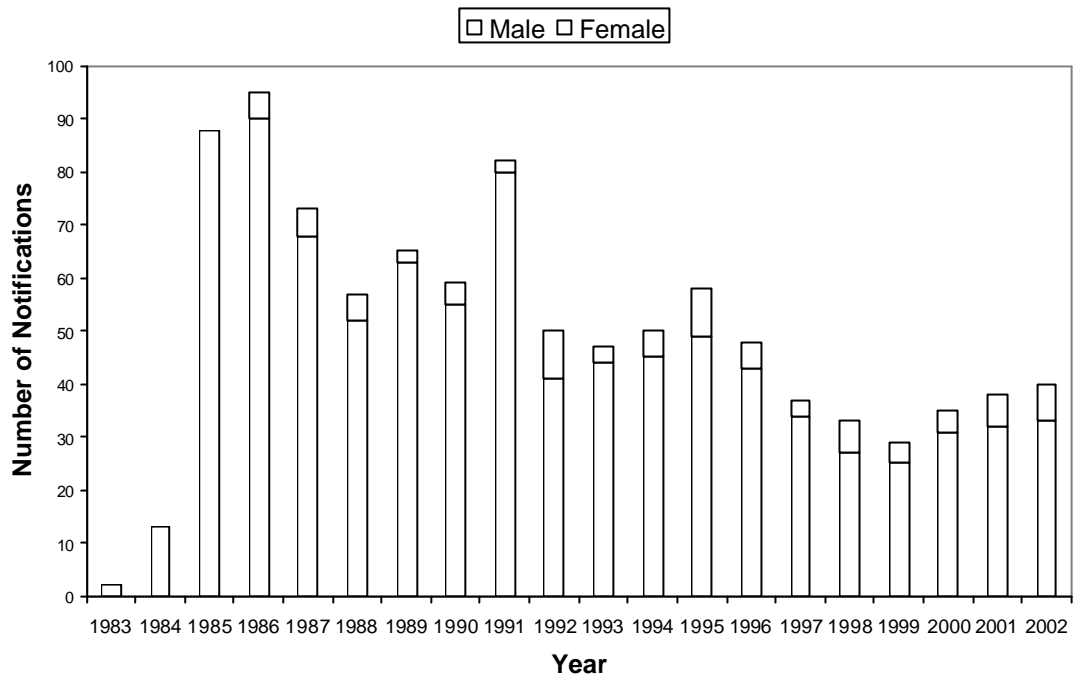
Figure 4: HIV notification rates for WA and Australia by Aboriginal Status, 1992–2002.



Source: Epidemiology and Surveillance, Communicable Diseases Control Directorate, Department of Health. 20/02/2004. Information from 1992 only, as prior to this date, national information regarding HIV diagnosis by Aboriginal status was incomplete and unreliable (National Centre in HIV Epidemiology and Clinical Research 2002).

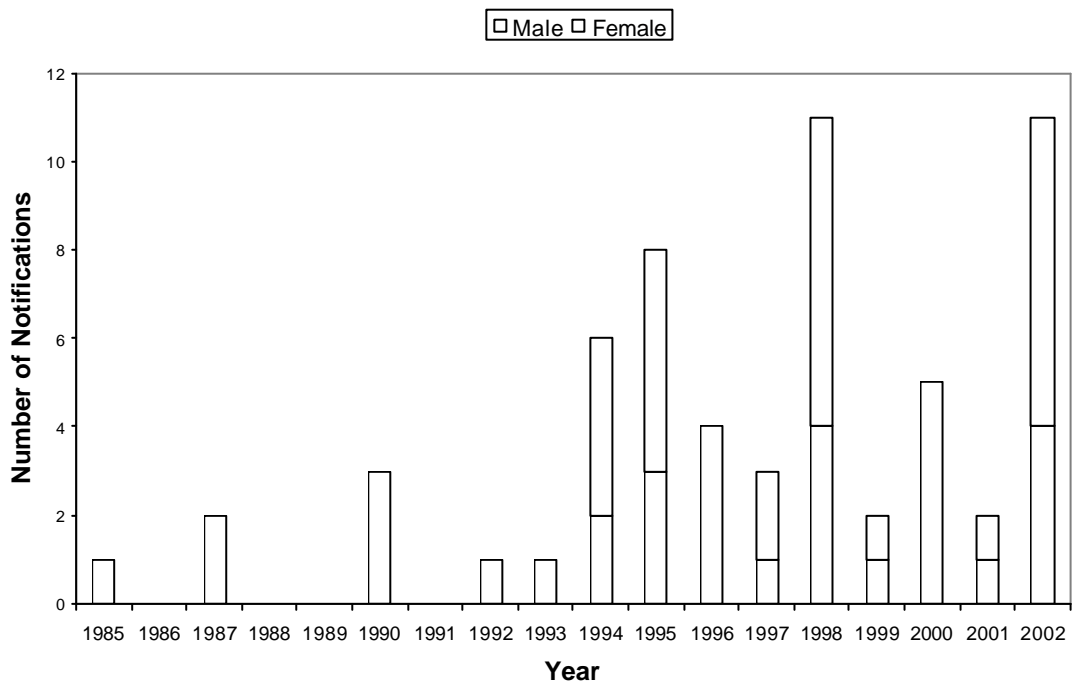
As well as different rates and trends of HIV infection, there are other differences in the epidemiology of HIV between Aboriginal and non-Aboriginal people in WA. Figures 5 and 6 show that the sex distribution of HIV infection is quite different, with a marked predominance of infections in males among the non-Aboriginal population and similar numbers of Aboriginal males and females infected. Age at diagnosis (Figures 7 and 8) shows a higher proportion of Aboriginal women have been infected at a younger age, as adolescents, compared to non-Aboriginal women, although older women have also been infected (Figure 8). Infections in Aboriginal men have been predominantly in the 30–39 year age group, whereas non-Aboriginal infections follow a more normal distribution, with the mode for HIV notification also being in the 30–39 age group. The differences in sex and age distribution can be largely attributed to differences in the route of transmission (Table 12). Whereas 68% of infections in non-Aboriginal men are attributed to homosexual exposure with an additional 5% in homosexual men who also inject drugs, in Aboriginal people 68% of infection is attributed to heterosexual exposure. Only 16% of HIV in non-Aboriginal people is attributed to heterosexual exposure and only 10% of the infection in Aboriginal people is attributed to homosexual exposure with another 10% to men who have sex with men and inject drugs. Injecting drug use accounts for 8% of transmission in Aboriginal and 5% in non-Aboriginal people in WA.

Figure 5: Number of non-Aboriginal HIV Notifications by Year and Sex, WA, 1983–2002



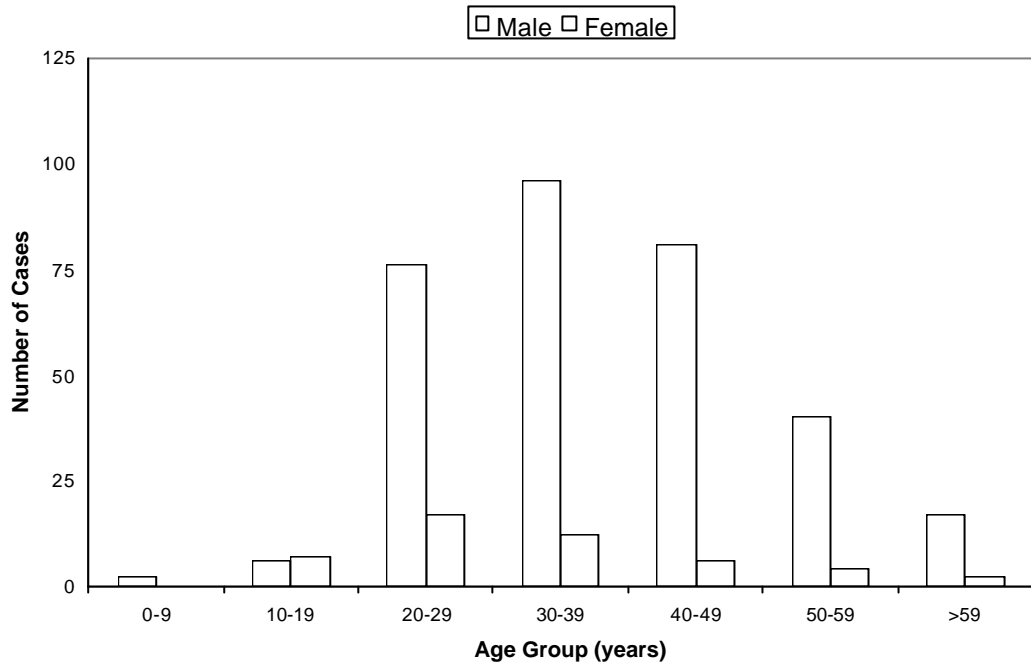
Source: Epidemiology and Surveillance, Communicable Diseases Control Directorate, Department of Health. 20/02/2004.

Figure 6: Number of Aboriginal HIV Notifications by Year and Sex, WA, 1983–2002



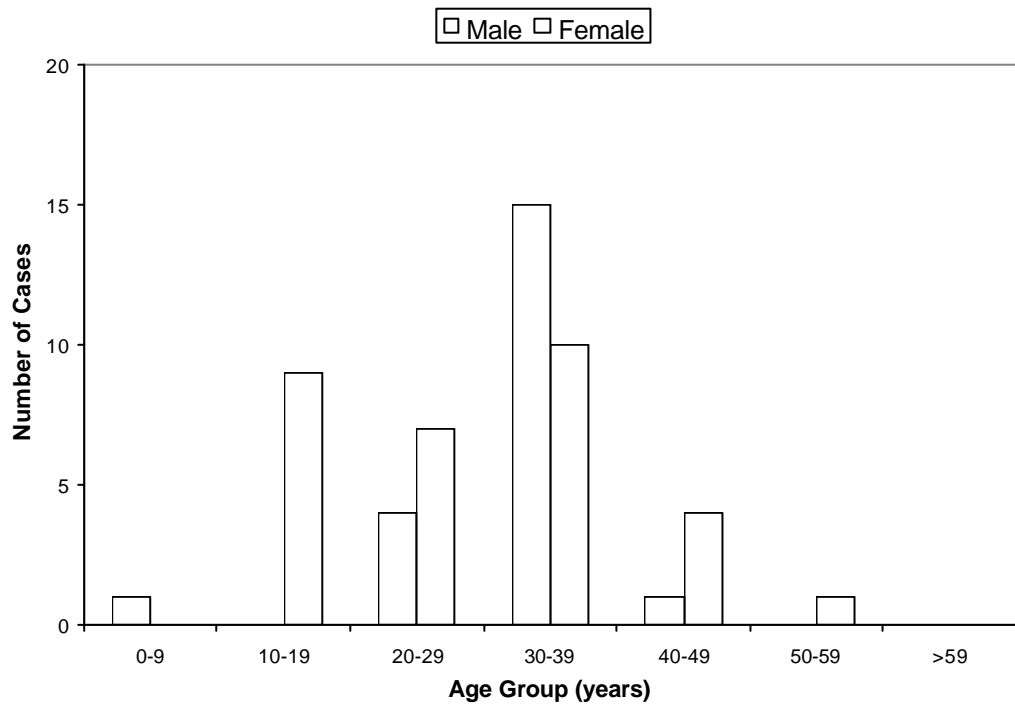
Source: Epidemiology and Surveillance, Communicable Diseases Control Directorate, Department of Health. 20/02/2004.

Figure 7: Age distribution of HIV infection, non-Aboriginal, WA, 1983–2003



Source: Epidemiology and Surveillance, Communicable Diseases Control Directorate, Department of Health. 20/02/2004.

Figure 8: Age distribution of HIV infection, Aboriginal, WA, 1983–2003



Source: Epidemiology and Surveillance, Communicable Diseases Control Directorate, Department of Health. 20/02/2004.

Table 12: Route of Transmission of HIV by Aboriginality, WA, 1983–2000

| | Aboriginal | | Non-Aboriginal | |
|---------------------------------|------------|-------------|----------------|-------------|
| | n | % | n | % |
| Men who have Sex with Men (MSM) | 6 | 10.0 | 682 | 68.1 |
| MSM and injecting drug use | 6 | 10.0 | 55 | 5.5 |
| Injecting Drug Use | 5 | 8.3 | 51 | 5.1 |
| Heterosexual | 41 | 68.3 | 158 | 15.8 |
| Vertical | 1 | 1.7 | 4 | 0.4 |
| Unknown /other | 1 | 1.7 | 20 | 2.0 |
| Recipient of blood products | 0 | 0.0 | 32 | 3.2 |
| Total | 60 | 100 | 1002 | 100 |

Source: Epidemiology and Surveillance, Communicable Diseases Control Directorate, Department of Health. 20/02/2004.

Appendix 2: Interview Guide

1. Can you think back to the few months before you were told you were HIV positive? What was your life like back then?
2. Can you tell me what was going through your mind when you were told that you have HIV? What things helped you cope when you first knew you had HIV? What things help you cope now?
3. Can you tell me what you knew about HIV before you were told that you had it?
4. What about now? Where do you get HIV information?
5. Can you tell me how HIV has affected your health?
6. Have you been given any medicines or tablets for your HIV?
7. Can you tell me how you look after your own health?
8. Who do you go to for HIV health care?
9. Who would look after you if you got really sick?
10. How many people have you told that you are positive? Who have you told?
11. Has anybody told others that you are positive, without getting your permission?
12. Do any of your family or relations treat you any different since you got HIV? What about other people?
13. Thinking back to the experience of telling other people you are HIV positive, (or choosing not to tell some people) what would you do differently?
14. Are there any other positive people you can talk to?
15. Do you have enough money for food and for everyday living?
16. Where are you living now?
17. Can you tell me how your finances or accommodation have changed because of HIV?
18. How has HIV changed the way you enjoy yourself?
19. How has HIV changed the way you socialise or meet new partners?
20. Did you have any children before you were diagnosed? Have you (or your partner) had a baby or have fallen pregnant since you were diagnosed? Were there any problems having baby? Were there any problems feeding baby because of HIV?
21. Can you tell me how HIV has changed the way you think about the future?
22. Can you tell me how HIV was passed on to you? How do you feel about getting it this way?
23. Did you think you were at risk of getting HIV?
24. Can you tell me how health services could be improved for Aboriginal people who have HIV?
25. What things do you think the Aboriginal community should know about HIV?
26. What would be the best way of doing that?
27. Are there any other things that could be made better for Aboriginal people who are HIV positive?
28. Can I ask how old you are? What's your language group / your mob? What about schooling?
29. In thinking over the whole experience of living with HIV, what has been the most important change that has taken place in your life?
30. What else would you like to say before we close the interview?

Appendix 3: HIV health services in Western Australia

Specialist medical care for people who are HIV positive in WA is provided through the Clinical Immunology Department at Royal Perth Hospital and the Department of Infectious Diseases at Fremantle Hospital. Despite the size of Western Australia, there is a high level of centralisation of HIV services and only a small number of general practitioners in WA have expertise in HIV care. Royal Perth Hospital Immunology Department has a statewide function, and coordinates specialist care for rural HIV positive people and for those who are in custody in Western Australian prisons. A Clinical Nurse Rural and Remote Coordinator is employed for this purpose.

The HIV positive participant who was a prisoner at the time of interview reported receiving specialist care through attendance at the Immunology Clinic at RPH approximately three monthly.

Western Australia has a “cluster” of Aboriginal people who are HIV positive and who reside in what is termed “the regional area of special need”. They access health care related to their HIV through the regional population health unit. Immunology Specialists visit the region on a three-monthly basis. An independent evaluation of the HIV/STD Program run in the region (Pitman 2000) noted that the program was characterised by:

- The provision of services by and through Aboriginal staff to the greatest extent practicable
- The provision of direct clinical care by staff, including a significant clinical component by the public health physicians
- Regular visits by immunology specialists
- A heavy emphasis on health education (at an individual level) and health promotion (at a group or population level)
- Continuous and close contact by population health unit staff and clients through case management, support and counselling
- Accessibility, including the provision of a free 1800 telephone number available for use only by clients.

Aboriginal people who are HIV positive and who reside in other rural areas receive assistance to travel to attend the Immunology Department at Royal Perth Hospital for specialist appointments approximately every three months. Day-to-day health care is provided by a variety of health services including general practitioners, Population and Community Health Staff, Aboriginal Community Controlled Health Organisations and regional hospitals.

Women who are HIV positive and who become pregnant are delivered at King Edward Memorial Hospital for Women, where specialist HIV obstetrical care is available. Princess Margaret Hospital provides specialist paediatric care for HIV positive children.

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