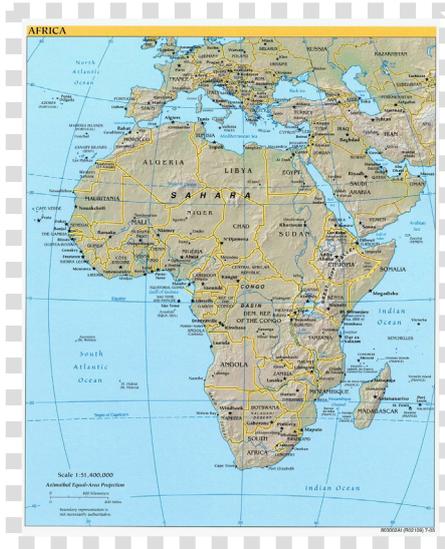

REDUCING THE RISK OF TRANSMISSION OF HIV/AIDS IN AFRICAN AND ARABIC-SPEAKING COMMUNITIES IN VICTORIA



FINAL REPORT

PREPARED FOR THE

VICTORIAN DEPARTMENT OF HUMAN SERVICES

SUBMITTED BY

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In collaboration with

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The Department of Medicine recognises that the findings of this report belong first and foremost to the communities that participated.

Note on publication:

This is an edited edition of the report submitted to the Victorian Department of Human Services in July 2006, entitled “Reducing the Risk of Transmission of HIV/AIDS in Victoria’s African and Arabic-speaking communities.” The content of this published edition is substantially the same as that of the report except for the following points:

1. Quotations are presented without details of the gender or ethnicity of each source. These details have been removed to protect the identity of participants and to avoid giving an impression that certain views are limited to a particular ethnic group. Unless otherwise stated, the statements quoted here were consistent between the different African communities.
2. Details of questionnaires, budget and approval certificates from Human Research Ethics Committees are not included. These documents are available on request from the Department of Medicine of The University of Melbourne, or from the Department of Human Services.

Errata:

A preliminary version of this report, circulated for comment, contained an error on page 6. This has been corrected in the current version. The phrase: “despite comprising only 9.6% of the population as a whole,” now reads “... despite comprising only **one percent** of the population as a whole.” The authors apologise for this error.

The authors would like to remind the reader that substantial advances in HIV research and management have occurred since the completion of this report in 2006. Some information contained herein may no longer reflect current scientific understanding, clinical practice or terminology.

The research team would like to thank all of you who participated in this study. If you do not see your own words quoted in this report, please do not be disappointed. Every person who took part in these interviews and discussions has made a real contribution to the final results, and this report would not have been possible without you.

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Abbreviations

AIDS	Acquired immune deficiency syndrome
CCREID	Centre for Clinical Research Excellence in Infectious Diseases
CRF	Circulating recombinant form
DIMA	Department of Immigration and Multicultural Affairs (since 2005)
DIMIA	Department of Immigration, Multicultural and Indigenous Affairs (until 2005)
DNA	Deoxyribonucleic acid
FGD	Focus group discussion
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
HSA	Health Services Australia
KII	Key informant interview
LANL	Los Alamos National Laboratory
MOC	Medical Officer of the Commonwealth
MHSS	Multicultural Health and Support Service
MSHC	Melbourne Sexual Health Centre
PCP	Pneumocystis pneumonia (formerly <i>Pneumocystis carinii</i> pneumonia)
PCR	Polymerase chain reaction
PICF	Participant information and consent form
PLHA	Person/people living with HIV/AIDS
RNA	Ribonucleic acid
STI	Sexually transmitted infection
SWI	Sudanese woman interview
TB	Tuberculosis
VIDS	Victorian Infectious Diseases Service

Executive Summary

HIV/AIDS is an issue of major global importance. Over 40 million people are infected with HIV worldwide, and the pandemic has had a huge impact on societies from the wealthy nations of Western Europe and North America to the economically disadvantaged nations of Africa, Asia and Oceania. Although some countries, including Australia, have been successful in limiting the spread of HIV/AIDS, established generalised epidemics exist in many regions of sub-Saharan Africa, and the number of people affected by the disease is rapidly rising in Eastern Europe, India, China, SE Asia and Papua New Guinea. In Australia, complacency is not in order, as a small but sustained rise in the number of newly diagnosed people with HIV infection indicates that public health authorities and government must be ready to respond to the dynamic problem of HIV/AIDS in this country.

The changing pattern of the HIV epidemic in Australia and the experience of health care professionals indicate the need for new research with culturally and linguistically diverse (CALD) communities to provide a basis for developing effective means of preventing new HIV infections, and to improve the care and support available for those already affected by HIV/AIDS. In 2004, in recognition of this need, the Victorian Department of Human Services (DHS) funded a number of research projects addressing the issue of HIV/AIDS in CALD communities.

This project was undertaken by the Department of Medicine of the University of Melbourne, in collaboration with the Burnet Institute, the Australian Centre for Research in Sex, Health and Society, and several organizations based in communities from the Horn of Africa and North Africa. This final report outlines the important findings we have made in the areas of knowledge and beliefs about HIV/AIDS in African communities in Victoria, as well as barriers to accessing health services and community support.

Background

The epidemiology of HIV/AIDS in Australia is changing. Although most Australians with HIV/AIDS are Australian-born men exposed through homosexual sex, recent years have seen an increase in the number of women, people infected through heterosexual

sex, and people born abroad in regions that have a high prevalence of HIV/AIDS, such as sub-Saharan Africa.

HIV/AIDS is an important issue for African communities, as it is for other CALD communities in Australia. The annual report on national HIV/AIDS surveillance produced by the National Centre in HIV Epidemiology and Clinical Research shows that, between 1999 and 2003, people born in sub-Saharan Africa were over-represented among new diagnoses of HIV infection in Australia: approximately a quarter of newly diagnosed people with heterosexually-acquired HIV were born in this region, despite comprising only one percent of the population as a whole. Late diagnosis of HIV was also a problem for this group: 60% of people born in sub-Saharan Africa were only diagnosed with HIV within three months of AIDS diagnosis. It is not clear when or where HIV-infected Australian residents born overseas actually acquire the infection, which presents difficulties when developing strategies for preventing new infections.

The experience of Victorian HIV/AIDS service providers suggests that African-born Australians living with HIV/AIDS often confront major issues such as stigmatisation, social isolation and inadequate social support. These issues must be understood in order to enable adequate delivery of care to this group of patients, yet little research has been carried out in this area.

Prevention of new HIV infection in the community depends on education of the public, yet the quantity and quality of multilingual information available to Australia's African communities about HIV/AIDS is far from adequate. This is borne out by a recently published study by the Australian Centre for Research in Sex, Health and Society, which attempted to gather information that would enable the development of effective HIV prevention initiatives in Victoria's African communities, and improve the care and support available to African Australians living with HIV/AIDS.

Aims

The overall aims of this study were to:

- Gain an increased understanding of the cultural context, specific risk factors for, and knowledge about HIV infection and its transmission in communities from the Horn of Africa and Arabic-speaking communities.
- Collect information and materials that will assist in the development of culturally appropriate methods for improving knowledge about HIV/AIDS, and access to and utilisation of health services by these communities.

Methodology

We conducted a community-based qualitative inquiry with communities from Ethiopia, Eritrea, Somalia, Sudan and Egypt. We completed 47 in-depth interviews with key informants from African community organizations, and service providers from health and welfare sectors. Themes emerging from these interviews were further explored in 17 focus group discussions with people from the Ethiopian, Somali, Sudanese and Eritrean communities, and service providers to these communities.

We have begun a series of interviews with African-born people living with HIV/AIDS in Victoria. The interviews explore circumstances of exposure to HIV, events leading to diagnosis, experiences since diagnosis, and response to treatment. Along with interviews, a molecular study will examine the characteristics of the virus strains carried by participants in the case series. This study will provide insight into the medical and social issues encountered by African-born people living with HIV/AIDS in Victoria, with a view to improving the quality of services and support for this group. It will also assist in developing a more accurate idea of the probable circumstances leading to infection with HIV.

Key findings

- African communities in Victoria have extensive knowledge and experience of HIV/AIDS in the African context. This derives from personal experience in Africa, as well as public health and media information exposure prior to migration.
- To African communities, HIV/AIDS is a highly contagious “killer” disease that affects immoral people, for which there is no effective treatment.
- Sympathy for PLHA is tempered by fear of contagion and death.
- Strategies used by African communities to avoid exposure to HIV include abstinence from extramarital sex, abstinence from sex with “high risk” partners, condom use with “high risk” sexual partners, and avoidance of all social or physical contact with people known or suspected to have HIV/AIDS.
- African immigrants (like Australian health workers) do not understand the process by which visas are granted or denied to PLHA, and believe that no HIV-positive people are allowed to settle in Australia.
- Compared to Africa, there is little media or public health information about HIV/AIDS in Victoria as it relates to local African communities.
- African communities view Australia as a country free of HIV/AIDS.
- African communities are more familiar with the term “AIDS” than “HIV”.
- African Australians in Victoria feel they are at less risk of exposure to HIV than other people.
- Unprotected sexual contact is the most important risk factor for HIV infection for African communities in Victoria.
- Delayed diagnosis of HIV/AIDS in African settlers to Victoria is due to low self-perceived risk of HIV infection, competing priorities of migration, settlement and health, and fear of the diagnosis of HIV/AIDS.
- Barriers to access to optimal treatment for African Australian PLHA are: stigma associated with HIV/AIDS; concern for privacy and confidentiality; and lack of access to well-trained, confidential, professional interpreters.
- A wide variety of means may be used to provide information to African communities, including community discussions, electronic/print media, and health workers.

Recommendations

1. Community education about HIV/AIDS is urgently needed and should emphasize the following points:

HIV does exist in African communities in Victoria.

The migration HIV screening of immigrants to Australia does not exclude HIV infection in the groups or individuals who have been screened.

HIV infection is not always due to what some people perceive as “immoral behaviour”.

HIV infection is not spread through casual contact, only through sex, HIV-infected blood, childbirth and breastfeeding.

A person infected with HIV may feel and appear well.

Treatment of HIV in Australia enables people living with HIV/AIDS to live much longer and be well.

People living with HIV/AIDS can have healthy, uninfected children, and their chances of this are better if they are being treated for HIV infection.

Community education should be provided in appropriate languages.

Community education about HIV/AIDS should be provided separately to males and females, older and younger people.

The moral context of HIV/AIDS and sexual health must be acknowledged and discussed during community education.

2. Interpreter and support services need to be strengthened and better integrated into health service delivery.

Health services must achieve good communication with the CALD clients of Victorian society, including African communities. This could be accomplished using well-trained and supported interpreter and bicultural support services to enable the provision of adequate health care and education for African people living with HIV/AIDS, and for members of African communities generally. Interpreter services must include sufficient numbers of people with sufficient fluency in both general and technical levels of appropriate community languages.

The training of interpreters and bicultural support workers should emphasise the importance of privacy and professional confidentiality in order to build trust within the community. The existence and reliability of confidential interpreter and bicultural support services must be well publicised within African communities.

Overall accountability and professionalism could be increased by ensuring that providers of interpreter and bicultural support services formally accept responsibility for monitoring the performance of their staff, and maintaining an adequate standard of practice.

3. Community involvement will improve and facilitate the delivery of specific HIV/AIDS services.

African communities need to be involved in the development of appropriate community education programs and materials, as well as the training of health care workers in refugee/immigrant health, and HIV/AIDS services. This will lead to the development of appropriate materials and services and will ensure the use of the services by communities. Involvement of communities is essential for the effective implementation of the recommendations above.

Project Overview

Background

The epidemiology of HIV/AIDS in Australia is changing. Most people living with HIV/AIDS in this country are still Australian-born men who have been exposed through homosexual sex; however in recent years the number of new diagnoses of HIV infection is increasing among women, people born in countries with a high prevalence of HIV, and heterosexually infected people. There is extensive overlap between these groups. In the period between 1999 and 2003, people born in sub-Saharan Africa represented approximately a quarter of heterosexually acquired HIV infections in Australia, while 60% of people born in sub-Saharan Africa who were diagnosed with AIDS were diagnosed late with HIV; that is, they were diagnosed of HIV within three months of AIDS diagnosis (2005).

In the 2001 census, one percent of Australians were born in Africa (2004). The largest groups of African immigrants to Victoria are long-established settlers from South Africa, Egypt and Mauritius. Since the 1980s, increasing numbers have migrated from the Horn of Africa (Ethiopia, Eritrea, Somalia and Sudan), many as refugees. The newer groups encompass a wide variety of ethnicities, languages, religions and educational backgrounds (2004).

As part of the immigration process, applicants for permanent settlement in Australia must pass a health requirement in order to receive a visa. The medical assessment for this requirement includes a test for HIV antibodies for applicants aged 15 years and over, and some others (children for adoption, and individuals with specific exposure history). Applicants for temporary residence do not have an HIV test unless they are intending to study or work in the fields of medicine or dentistry. HIV infection is a condition deemed to pose a significant cost to the Australian health system, and its diagnosis during health screening leads to the applicant's failure of the health requirement for migration. However, applicants who fail the health requirement are able to request that it be waived, to allow settlement in Australia. In addition, there is no health requirement for an onshore protection visa; applicants are medically assessed in order to estimate the extent and cost of their health care needs (Kulkarni 2004).

Although the number of African-born people living with HIV/AIDS (PLHA) in Australia is small, it is important to provide African communities with information that will enable them to reduce their risk of HIV exposure. However, little information is currently available about HIV/AIDS in the various African languages spoken in Victoria (Dutertre and McNally 2006). Also, the circumstances of potential HIV exposure and the level of existing knowledge about HIV/AIDS must be taken into account when developing community health education materials.

Aims

The overall aims of this study are to:

Gain an increased understanding of the cultural context, specific risk factors for, and knowledge about HIV infection and its transmission in culturally and linguistically diverse communities in Melbourne.

Collect information and materials that will assist in the development of culturally appropriate methods for improving knowledge about HIV/AIDS, and access to and utilisation of health services by these communities.

The research questions and objectives are:

1. *What are the knowledge, attitudes and practices regarding HIV in settlers from Africa?*

Objectives:

- 1.1. Describe the knowledge, attitudes, practices and beliefs of Victorian settlers from Africa regarding HIV and sexually transmitted infections (STI) and their relevant health care services.
- 1.2. Describe the prevalence of risk factors for acquisition of HIV and STI amongst these communities and identify risk groups within communities that will benefit most from public health initiatives to improve understanding of HIV and its transmission.
- 1.3. Determine the level of awareness and concern within these communities regarding HIV and STI, including the perception of a need for behavioural change in order to reduce the risk of acquisition of these infections.

2. *Do these settlers face barriers to early diagnosis and optimal management of HIV, leading to an increased burden of disease?*

Objectives:

- 2.1. Identify and describe barriers faced by people from these communities in gaining access to timely diagnosis and optimal treatment of HIV and other STI.
- 2.2. Describe the burden of physical and psychosocial illness of PLHA from African countries and compare this to that of other Australians living with HIV.

3. *What are the perspectives of healthcare workers serving people living with HIV from these communities, regarding cultural, social and physical aspects of HIV, and difficulties in providing optimal treatment?*

Objectives:

- 3.1. Describe the perceptions of healthcare workers serving PLHA from these communities, regarding cultural, social and physical aspects of HIV, and difficulties in providing optimal treatment.

4. *What opportunities and methods are available to increase knowledge and awareness of HIV amongst these communities in order to decrease the risk of new infections?*

Objectives:

- 4.1. Identify the current means used by Victorian communities from African backgrounds to obtain information and advice regarding HIV and STI.
- 4.2. Identify the best methods and resources for use in increasing community awareness of issues surrounding HIV and STI and for implementing public health initiatives aimed at reducing the spread of HIV in these communities.

Methodology

Participatory approach

In order to facilitate access to and cooperation with the diverse African communities of Victoria, the study focused on those from Ethiopia, Eritrea, Sudan, Somalia, and Egypt. Within the African communities, a participatory approach was adopted. The benefits of this approach have been seen in the active cooperation of African community members in investigating a topic that has previously either been seen as taboo, or not warranting urgent investigation. The following organizations have been contacted to date, and have actively participated in the research project: Family and Reproductive Rights Program, African Australian Welfare Council of Victoria, United Somali Women, Horn of Africa Senior Women's Group, Sudanese Community Association of Victoria, Dinka Jieng Community Council of Victoria, and the Oromo Community Association in Victoria.

Methods

Two separate, though related studies were developed:

- * Firstly, a qualitative community-based inquiry used in depth interviews and focus group discussions to explore the knowledge and attitudes regarding HIV within the communities, the perspectives of service providers to these communities, and sources of information about HIV/AIDS and sexual health.
- * Secondly a case series of African-born PLHA looked at risk factors for acquisition of HIV infection, factors delaying diagnosis of HIV infection, management of HIV, and sources of information about HIV/AIDS.

Community study

The study population for this inquiry consisted of:

- * Leaders and members of African and other immigrant community organizations in Victoria
- * Service providers to these communities
- * People belonging to groups at potential risk of HIV infection
- * Media organizations serving immigrants and refugees, including African communities
- * Service providers to PLHA

Recruitment was purposive, seeking informed sources that were willing to talk frankly about the sensitive issue of HIV/AIDS, and were in a position to be aware of relevant issues in African communities. The process of snowball recruitment began with the recruitment of research assistants. Most were members of community groups from the Horn of Africa, and also service providers in the areas of settlement or welfare. After discussion of the research aims and objectives, team members nominated members of their communities and others whom they felt had knowledge of relevant issues. These individuals were contacted as key informants for in depth interviews in a flexible format based on a topic guide, but able to explore emergent issues. These first key informants were asked to nominate further informants, who were then asked to do the same.

Research assistants and some key informants were asked to identify potential participants for focus group discussions. Recruitment for interviews and focus group discussions continued until at least one perspective had been gained from each of the major ethnic, religious, linguistic, gender and age sections of the communities from the Horn of Africa and Egypt, and “theoretical saturation” had been reached (i.e. no new issues emerged from interviews and discussions, that had a bearing on the research questions).

The interviews and discussions were carried out face-to-face, by one or two researchers, in the language(s) in which participants felt comfortable to express themselves. Interviewers and facilitators were generally of the same gender as the participants, except where the participants stated that they felt comfortable to discuss issues of HIV/AIDS and sexuality with a particular researcher.

Audio recordings of interviews and discussions were made of all interviews and discussions, and verbatim transcripts were made. Where necessary the English translations of the transcripts were also produced. Informed consent was obtained from all participants. Participants were offered \$25 to \$30 reimbursement for costs and time involved in participation.

[Note on translation: English transcriptions and translations of interviews and discussions did not always conform to the norms of “standard” Australian English.]

Spelling has been corrected, but other alterations have been made only where the meaning of the original was unclear.]

To analyse the data transcripts, names and details identifying all participants and some institutions were removed from copies of the transcripts, which were then entered into qualitative data analysis software package HyperRESEARCH version 2.6 (ResearchWare Inc, Randolph, USA). Transcripts were analysed thematically.

Outline of thematic analysis

The research questions were examined, and a priori themes were derived, which addressed all aspects of the research questions. Lines of inquiry were developed from these a priori themes, for use in interviews and discussion groups. The a priori themes are listed below.

A priori themes

1. Risk factors for HIV infection
 - a. Sex
 - b. Blood
 - c. Mother-child
2. Delayed Diagnosis of HIV infection
 - a. Risk perception
 - b. Access to services
 - c. Consequences of diagnosis
3. Social support for PLHA
 - a. Community
 - b. Services
 - c. Other PLHA
4. Information about HIV/AIDS
 - a. Current
 - i. Sources
 - ii. Content
 - b. Preferred
 - i. Sources
 - ii. Content
 - iii. Issues in delivering information

The text of transcribed interviews and discussions was coded, and 49 emergent themes were derived. These emergent themes were then linked to the a priori themes, in order to pursue fruitful lines of inquiry in subsequent interviews. There was overlap and duplication between these themes, as some emergent themes were related to several of the a priori themes.

People living with HIV/AIDS - a case series

We have begun a series of interviews with African-born PLHA in Victoria. The interviews explore circumstances of exposure to HIV, events leading to diagnosis, experiences since diagnosis, and response to treatment. Along with interviews, a molecular study will examine the characteristics of the virus strains carried by participants in the case series. This ongoing aspect of the research is supported by the Centre for Clinical Research Excellence in Infectious Diseases, and a Victor Hurley Grant-in-aid awarded by The University of Melbourne.

The Victorian HIV Registry has been contacted and has provided a list of name codes, country of birth, and notifying doctor, for people born in Africa, notified as diagnosed with HIV infection, and not notified as deceased. 146 cases have been found. In order to preserve anonymity, eligible people are not approached directly by the research team. Instead, treating doctors are contacted by the research team and are provided a list of name codes of eligible individuals notified from or referred to their clinic. Treating doctors then contact their African-born patients and ask their permission for contact by the research team. When this permission is given, a member of the research team contacts the patient either in person during a clinic visit, or by telephone (if requested by the patient) to explain the nature and purpose of the research project. Informed consent is sought for interview, review of medical records and test results, and access to stored blood samples for analysis of HIV. Consent is also sought for fresh blood samples to be obtained if stored blood is unavailable or unsuitable. This is a slow process and recruitment is expected to continue throughout 2006.

Results and Discussion

The results of the community survey and preliminary findings from the case series are presented below.

Participant characteristics

Participants in the community study contributed a variety of perspectives on Horn of Africa and North African communities, including health, immigration, social services, religious leaders, and members of the various communities. The characteristics of key informants and focus groups is summarised in the tables below. The case series participants are also described.

Community study participants

Table 1 Key informants

Demographic characteristics of key informants:		
Characteristics	Detail	Number
Gender	Male	15
	Female	32
Age group	Senior	41
	Youth	5
Community	Ethiopian	6
	Eritrean	5
	Somali	5
	Sudanese	20
	Egyptian	6
	West African	2
Service providers	Non-African	3
	Health	8
	Welfare	13
	Immigration	1
	Religion	2

Total number of cases: 47

Total number of participants: 45

Case with same participants: KII3/SWI1; SWI4/SWI13

“Ethiopian” includes Oromo and Harerean groups.

“Sudanese” includes groups from North and South

Table 2 Focus groups

Number	Community	Age	Gender
1	Ethiopian	Youth	M/F
2	Sudanese (N/S)	Senior	F
3	Sudanese (S)	Senior	M
4	Welfare sector	N/A	M/F
5	Sudanese (S)	Senior	F
6	Somali	Senior	F
7	Ethiopian	Youth	F
8	Ethiopian	Youth	M
9	Ethiopian	Youth	M/F
10	Sudanese (N)	Senior/Youth	M
11	Somali	Senior	F
12	Somali	Senior	M
13	Somali	Youth	F
14	Somali	Senior/Youth	M
15	Somali	Senior	F
16	Eritrean/Somali/Sudanese	Youth	F
17	Eritrean/Sudanese	Youth	M

Size of groups varied from 3 to 10 participants.

“Senior” refers to participants no longer considered children within their communities. This included married people and people older than approximately 35.

“Youth” refers to participants who were considered by their communities (or considered themselves) to be young people, not responsible adults. This included some secondary and tertiary students, and some people who had left school or were working. None were married, although some had children.

“Sudanese (N)” and “Sudanese (S)” refer to participants originating from the “North” (who were mainly Arabic-speaking and Muslim), and those from the “south” (mainly Dinka- or Barre-speaking, and Christian). The distinction between north and south varied in its importance to participants.

Case series

Victorian HIV Registry

Eligible individuals notified between 1 Jan 1996 and 30 April 2005

N = 146 (92 male, 54 female)

Country of birth: Ethiopia 45; Somalia 5; Sudan 5; Eritrea 3; Egypt 1.

Diagnosed during immigration screening: 18

Approached by treating doctor: 11

Verbal consent for contact: 8

Refused contact: 3

Interviewed: 3

In the following discussion, emergent themes are related to research questions and objectives, with illustrative quotations from transcripts where appropriate.

Research questions

1. Knowledge, attitudes, beliefs and practices regarding HIV/AIDS
 - 1.1. Knowledge, attitudes, and beliefs
 - 1.2. Practices
 - 1.2.1. Protective strategies used to prevent HIV infection
 - 1.2.2. Behaviour toward PLHA
 - 1.3. Risk factors and risk groups for HIV infection
 - 1.4. Level of awareness and concern about HIV/AIDS
2. Barriers to diagnosis and treatment
 - 2.1. Barriers to early diagnosis and optimal treatment of HIV/AIDS
 - 2.1.1. Barriers to early diagnosis
 - 2.1.2. Barriers to optimal treatment
 - 2.2. Burden of illness
3. Perspectives of health workers
4. Increasing knowledge and awareness of HIV/AIDS
 - 4.1. Current information about HIV/AIDS
 - 4.2. Methods for providing information to African communities

1. Knowledge, attitudes, beliefs and practices of African communities regarding HIV/AIDS and STI

This research question explored the current knowledge of HIV/AIDS within African communities, the attitudes and behaviour toward PLHA, and the actual practices or behaviour adopted by members of African communities that either place them at potential risk of exposure to HIV infection, or are adopted as strategies to avoid such exposure.

1.1. Knowledge, attitudes and beliefs regarding HIV/AIDS

People know “AIDS” but not “HIV”

Participants reported that, due to public health information, and media, both in Africa and Australia, members of African communities think and talk about “AIDS” rather than “HIV”.

- In Sudan, that's it, people know this disease not as “HIV” but as “AIDS”, yes, that's the well-known for all the Sudanese people.

- OK. Do you know what HIV is?

- I think it is AIDS itself, but in the term of the language of the scientist
SWI13, Sudanese woman

- No, we didn't say "HIV." HIV... mostly we say, "AIDS"... "AIDS"... "AIDS"... "AIDS".

KII18, Young Ethiopian woman

Much public health and media material in Australia refers to “HIV” rather than “AIDS”. Members of African communities may not realise that information about “HIV” refers to what they view as “AIDS”. This information will thus fail to reach them. In addition, the quantity of visible information about “AIDS” may seem limited, leading to a perception that this disease is not a high public health priority in Australia. Other results from the current study suggest that this is in fact the case.

Killer disease

According to participants, African Australians think of HIV/AIDS as an almost uniformly fatal condition.

It is a killer disease, make you very thin, weak, and take away all your capability against diseases and the end you will die.

FGD3. Sudanese men

Some think that death will occur soon after infection; others are aware of the prolonged asymptomatic phase.

HIV is when the virus has contacted the blood, and the person appears healthy until 20 to 15 years, but when the body defence weakness, it is when it becomes AIDS.

FGD6, Somali women

Members of African communities seem to regard a person diagnosed with HIV/AIDS as effectively dead.

... if the person get the disease, we see it as the end of the person's life, whether the person will live 15 years or not.

FGD6, Somali women

The image of HIV/AIDS is thus linked with death, and the fear of death leads to fear of people affected by the disease, and a tendency to extreme caution in avoiding exposure to the disease.

In addition, the influence of fear on the thinking of community members cannot be countered by mere factual information. Active steps to reduce fear are required, and the temptation to use fear as motivation for behavioural change should be resisted.

Contagious disease

HIV/AIDS has an image within African communities of being highly contagious, able to spread from one person to another by simple touch, sharing household utensils, toilets and so on.

... We have heard about all ways that disease to be transmitted from sick person. Like syringes, blades and sexual contact, if you used the same toilet that was been used by sick person with HIV or if the flies or mosquitoes sat in a wound and flew to another person's wound who is not sick, the person who sick will get HIV. We do not know if it is true.

FGD3, Sudanese men

The person living with HIV/AIDS is seen as a threat to any people who come into contact, such as family and friends.

... if someone has the disease comes or enters we become alert, even we think you can get the disease by touch of the person. May God treat the sick one and prevent the disease from others.

FGD6, Somali women

Together with the perception that HIV/AIDS is almost always fatal, this image of the disease is a fearful one; this is a major contributing factor to the fear induced by HIV/AIDS, and the avoidance of PLHA by their communities. Since HIV is not, in fact, a highly transmissible infection, and spreads through a limited number of routes, the actual risk to people in contact with an HIV-infected person is almost nil, unless they are sexual partners or have contact with each others' blood. More accurate information about the risk of contagion may reduce the fear of HIV/AIDS in African communities, enabling them to maintain contact and support of PLHA, but as discussed above, fear itself must be addressed as an issue.

HIV transmission

Knowledge of HIV transmission was substantial, but not always accurate. In general, people seem to know how HIV is transmitted: sexual contact; blood-borne means (needle-sharing, blood transfusion), and mother-to-child.

However, many people think that HIV is also transmitted by numerous other means, as mentioned above.

Personally I have concerns about HIV although I have worked with doctors and have some background education. For some reason I cannot help it, I think it can be transmitted into any ways. I have heard and know, and many doctors told me that blood transfusion, uncleaned medical equipment can transmit the disease, also sharing of needles, unprotected intercourse can transmit the disease. However I still thought, God forbid, kissing of partner can be dangerous, saliva can transmitted. I have been told hundreds of times, and I read it in many places, but I cannot stop that thought in my mind that if a mosquito bit somebody who had the disease can be transmitted in that way. I am not sure. I have that concern.

FGD6, Somali women

Some of the people they, even if they heard so and so got AIDS they don't have to come next to that person, they thought that maybe shaking hands or even by breath that will separate that, they are very scared to, to hear about it.

SWI7, Sudanese woman

Most public health information concentrates on how HIV is spread, rather than how it is not spread. Given that the fear of contagion seems to be a major contributing factor to the general fear of HIV/AIDS in African communities, it is important to tell people how safe they are in most circumstances of contact with PLHA, and to specifically address the various routes of transmission that are erroneously thought to exist.

As can be seen from the data above, fear of contagion may persist despite provision of factual knowledge about proven transmission routes for HIV infection.

Association with “bad people”

The image of HIV/AIDS is associated with “bad people” in African communities, such as: people who have had multiple sexual partners, engaged in extramarital sex (either premarital sex, or sex with a person other than their spouse), homosexuals, (mainly male) prostitutes and their clients, and injecting drug users.

I know you can get through sex, particular when you are having sex and you shouldn't be.

KII31, Egyptian woman

HIV especially has a bad name, because many believe the victims are only homosexuals or people who go out and have sex with prostitutes, so if they hear you are HIV positive, they will try to connect it with that area.

KII26, Somali man

- I suppose people that are involved in drug use and that and that have contracted the disease, then I suppose they went ahead and made that decision and now you

have that, so yeah I suppose I would say depending on the circumstances, I may say that person did something wrong.

KII27, Egyptian woman

These associations lead to PLHA being judged as immoral by virtue of their diagnosis; in a sense, the disease identifies people who do not follow the guidelines of acceptable behaviour within their communities.

As I said to you, the image of HIV in our country is very terrible, you know? Because they think that if, oh... this person got HIV, the only thing they think about that he is not a good person.

KII3, Sudanese health services provider

PLHA in African communities are thus isolated because of presumed character faults, as well as fear of contagious biological infection. This association must be addressed in order to reduce the stigmatisation and social isolation of PLHA within African communities.

Association with loss of tradition

For older members of African communities, HIV/AIDS risk in Australia is linked to the loss of respect for and conformity with traditional standards of sexual morality. They fear that young people are placing themselves at risk of infection by engaging in premarital sex. This is associated with other socially undesirable behaviour such as drug and alcohol use.

Some who grow here are more likely to challenge the parent. They are more likely to have a boyfriend or girlfriend. They are more likely to disobey the culture that the parent (the father) wants them to live. They are more likely to have Australian friends and become open to illicit drugs. They are more likely to leave home while young, with the help of DHS.

KII26, Somali man

For African immigrants to Australia, the need to adjust to life in a new culture is a difficult process. Older people, particularly, are concerned that younger members of their communities may start behaving in ways that are not consistent with traditional standards of sexual morality and use of alcohol and drugs. They are also concerned about the erosion of the traditional authority and role of elders in African communities.

-This is the country of freedom, the freedom that leads you to death.

- This is the country of freedom. Us the parents, we stopped talking; they go do whatever they are doing, If they got sick, it is their responsibility, not ours.

- They will die.

- Usually the girl goes around and only comes to you when she is pregnant [with big stomach].

- The boy says, "No," and the girl says "No." They have become like devil. You even get the feeling that it is not your child, seriously... and they guess what time they come, always: "I am going to my friend," "I am going to my friend." I just hope we do not have to hear bad news later.

FGD2, Sudanese women

Migration to a new country entails adjustment to new ways of life, and exposure to social norms that may be at variance with previous experience. However, fundamental beliefs about what is right and wrong, particularly regarding sexual behaviour, are unlikely to change. Although the day to day views and core moral values of Australian society (such as the importance of marriage, and disapproval of sexual promiscuity) are probably not too different from those of traditional African societies, the open display of sexual material in the media may lead immigrants from countries where such displays are less common to believe that only retention of traditional values and customs will prevent immoral and dangerous behaviour, particularly by younger members of their communities.

“Openness” in Australia and modern African countries

- *the instincts are stimulated 24/7... I mean the TV shows see are titillating... on street you see people ... I mean girls wear short clothes so the person is always busy, recalling these images. So I think it is an important point.*
- *as ** said here, there is a spotlight on this thing in the advertisement... TV shows, movies or even the people walking on streets or the popular fashion these days.*
- *it becomes like competition... sort of competition.*
- *even the companies bring beautiful girls in these competitions to attract people.*
- *That's right. For a person coming from our societies and our countries...when he comes and find himself in the middle of this situation it becomes very difficult for him.*

FGD10, Sudanese men

Particularly for older members of African communities, the apparent increase in premarital sexual activity is attributed to the culture of “openness” in Australia, regarding discussion and acceptance of extramarital sex, homosexuality, and discussion of these issues in the media.

Young man and girls are the problems now. The question is: how to help them? Because they have been affected by open sexual relation.

FGD3, Sudanese men.

Of course in every country there is bad things. However here they have the freedom to engage in such activities and this is wrong. In Egypt it is wrong, so that is why they are in hiding and cannot show their faces to people. Anything that you cannot show themselves in front of people then it is wrong.

KII31, Egyptian woman

However, some participants did describe changing behaviour among young people in their countries of origin, suggesting that the process of change is underway in Africa as well as Australia. This may be particularly relevant to people who consider moving back “home” to prevent their teenage children from engaging in unsanctioned sexual behaviour.

In south Sudan in Juba City, if you do not drink alcohol, you will not get girlfriend. Many people drinks alcohol to get a girlfriend. I think the same things are happing here in Australia. Most of the girls here drink alcohol and drugs. If you do not what they are doing you cannot make friendship with them.

FGD3, Sudanese men

Also, the condemnation of homosexuality, for example, is not as universal in African countries as many of the members of local African communities themselves may think.

Yes, they are segregated. We don't intermingle with them, but they are respected as gays. If they say, "We bash gays," no, that's false. It's not true. Yeah. We've got our own gays, and we are... they are well respected within the community.

KII19, Somali man

Although some participants viewed "openness" negatively, others pointed out the increased ability to discuss matters of sexuality as beneficial.

... the kids who grow up in Australia, they are more open, and talk about things...

KII2, Eritrean man

From this it can be seen that there is a perceived contrast between socially conservative African cultures and a more open Australian culture, particularly regarding sexual behaviour and discussion about sex. However, neither culture is monolithic or static. There is more diversity in African cultures than may seem apparent; similar tension between conservative and liberal elements are present in Australian culture; neither culture remains unchanged over time, and the benefits as well as the dangers of "openness" are understood to varying degrees by African communities. Health educators and other should not be deterred from raising issues of sexuality, but should engage community members in discussions that provide an environment for free discussion of complex issues in a non-threatening atmosphere.

Knowledge of disease process

Most participants understood the general nature of HIV disease: a viral infection that leads to a weakened immune system, rendering the HIV-infected person vulnerable to other diseases. Those that distinguished between "HIV" and "AIDS" generally agreed that "HIV" either referred to the virus itself, or denoted an early stage of illness, compared to "AIDS", which was late stage, symptomatic, and resulted in death, if untreated.

When your immune system goes down to some level, if that drops that is when AIDS come and hospitalised. HIV is an infection, the virus in your blood system.

FGD1, Ethiopian men and women

AIDS is level that HIV was infected the person for long period or the final stage. When people said that person has been affected by AIDS, it means that all the symptoms of AIDS appeared on person's body.

FGD3, Sudanese men

- HIV is a disease caused by a virus. It's also known as human immunity deficiency, HIV is a disease fatal, and can be easily transmitted.

- HIV is a killer disease which can be easily transmitted from person to person.

- Is a virus which enters in the blood and then transform to AIDS, which can kill people.

FGD6, Somali women

It seems that previous health information about HIV/AIDS has had an impact on the understanding of African communities. These concepts are quite complex, yet people from a variety of cultural and educational backgrounds were able to provide a generally accurate brief summary of the nature of HIV/AIDS and how the virus causes human illness. This indicates the feasibility of discussing other complex concepts about therapy and transmission in the Australian context.

Physical manifestation of HIV/AIDS

Participants varied in their knowledge of an asymptomatic phase of HIV disease, in which it is not possible to tell that a person has HIV infection. Most knew that this phase existed, but its duration was put at anything from months to several years. Regarding symptomatic HIV, or “AIDS”, most mentioned weight loss, and some mentioned weakness. Interestingly, many of those with personal experience of HIV-related disease in Africa were from southern Sudan. The symptoms mentioned were generally weight loss, change in skin colour, pimples, skin ulcers, vomiting and diarrhoea. Most participants viewed diarrhoea as a pre-terminal event, with death following soon after.

First thing you got diarrhoea, seven or eight days. After that, your weight is going down. Just six months, maybe you will die. That is what they know about AIDS.

KII7, Sudanese man

The symptoms are: very high fever, rough skin, soft hair, chronic headache. At end, chronic diarrhoea and when the person infected reached this stage the person will die immediately.

FGD3, Sudanese men

It is difficult to identify specific opportunistic conditions from such secondary reports, but kala-azar, or visceral leishmaniasis, is a systemic parasitic infection prevalent in Sudan, that is well-described as an opportunistic infection, causes skin pigmentation and skin eruptions, mucosal lesions, has a poor prognosis and is difficult to treat in resource-poor settings. However, there are other possible opportunistic infections that could produce similar signs and symptoms, such as disseminated tuberculosis. It is important to bear in mind the patterns of HIV-related disease in Africa when discussing HIV/AIDS in Africa Australians, because the evidence of HIV infection in the Australian setting (where diagnosis may be made early, and treatment may prevent severe immune deficiency) is often in the abstract form of test results and milder symptoms, rather than the florid illness known to many African immigrants. Unless a health care provider can adequately explain the reason for the absence of well-known symptoms and signs of HIV/AIDS, a patient may doubt the diagnosis, leading to many areas of misunderstanding and conflict with health care providers.

Awareness of treatment

Many participants were aware of the existence of treatment for HIV infection, but few viewed treatment as effective in maintaining health.

... it is a disease without a cure. I mean if you have AIDS you can die, and treatment is difficult.

FGD2, Sudanese women

AIDS is a dangerous disease and killer too: if a person infected it difficult to cure. We heard that there is medication, but it is still dangerous.

FGD3, Sudanese men

Most felt that therapy extended life, but did not see this as a major benefit.

Just buy yourself a bit of time, because what it does, it takes time off you...

FGD9, Ethiopian young people

This may either be seen as a longer life but one in which a person with HIV/AIDS still feel unwell, or it may be that the physical aspect of HIV infection has less impact on the overall quality of life than the psychological and social aspects, which are not directly responsive to antiretroviral therapy.

Sometimes it's not the disease that kills you... the stress that you get out of it.

FGD9, Ethiopian young people

No participants mentioned the impact of treatment on reducing risk of ongoing transmission of HIV to sexual partners.

Improving community awareness of antiretroviral treatment is an important opportunity for improving the social situation of African Australians living with HIV/AIDS. Aspects that should be emphasised are: the ability for PLHA to remain well and live active lives on antiretroviral therapy; the reduced infectivity of PLHA who are successfully treated with antiretroviral therapy; the possibility for PLHA to having healthy, uninfected children, if successfully treated.

Prognosis of PLHA

African communities are aware that the prognosis of untreated symptomatic HIV disease is poor, particularly after AIDS has developed. However, they are less aware that treatment with antiretroviral therapy can improve this prognosis – either preventing development of AIDS, or enabling recovery from AIDS and remaining alive and relatively asymptomatic even after a diagnosis of AIDS, if effective therapy continues.

... HIV when it becomes AIDS and usually people say it is untreatable.

FGD6, Somali women

- Because it is a disease without a cure. I mean if you have AIDS you can die, and treatment is difficult.

- So when someone has AIDS it is really hard.

- The disease cannot be treated.

- If you have AIDS it is really hard.

- It doesn't have cure.

- Even the doctor doesn't know how to treat it, so the person just dies.

FGD2, Sudanese women

In this setting the perception of HIV/AIDS is similar to the lay perception of cancer – oncologists are familiar with the need to emphasise the treatable nature of many malignancies, and allay fears of prolonged suffering and death that accompany the diagnosis of “cancer”. By contrast, a condition such as diabetes mellitus, that is incurable, requires complex long-term treatment, and increases risk of serious illness and death, is often viewed with less anxiety. The perception of a condition may be as much due to the nature of the information provided to affected individuals and communities, as it is to the nature of the disease itself.

Mother-child transmission

Participants knew that mother-to-child transmission of HIV does occur. They reported that this was commonly known in their communities.

... some are know, because the blood is... the blood from the mum can go through... can go from the mum to the child, inside the... his mum. They know that.

KII7, Sudanese man

What was less well known was that, even in the absence of antiretroviral therapy, not all babies born to HIV-infected mothers go on to develop HIV infection. The further reduction in mother-to-child transmission achieved with antiretroviral therapy is even less well known.

... there is close monitoring from United Nations' workers to mothers, in order to make sure if you have AIDS that the foetus is healthy and therefore they monitor the pregnancy until the child is born; and when the child is born they stop the mother from breastfeeding the baby. This is the prevention...

FGD2, Sudanese women

But when I heard, that the have live babies, and the mother is with the virus, but the baby out there all right, that's for me... I don't understand. Yeah. And most people, especially from my community, I don't think they understand.

KII18, Young Ethiopian woman

Fertility and childbearing are often key aspects of life plans for both men and women from African (and other) communities. Widespread awareness of the ability to have healthy children despite HIV infection may play an important part in changing attitudes about HIV/AIDS in Victoria's African communities.

Sympathy for PLHA

There does appear to be sympathy within African communities for people living with HIV/AIDS, particularly those in Africa, but this is tempered by fear.

...I feel sorry for them, but I don't want to hear it.

KII2, Eritrean man

We are fearful of AIDS and when we come across person with AIDS we pray God for them and we avoid them, we prayed for God not to contract the disease.

FGD6, Somali women

Some participants mentioned the global context and the inequity of access to treatment in the developing world, compared to industrialised nations. The refusal of permanent residency visas to people diagnosed with HIV infection during immigration applications was mentioned; participants viewed this as a virtual death sentence for such people, who would be unable to access treatment for their condition, and would also face the stigma and isolation of their communities once the diagnosis was known.

I am confused: why the Australian government allowed some to come and not allowed others? For those who infected and kept away not to come to Australia, these people they really need help from Australia government, because the bad condition they living in overseas is too dangerous to them, no medications that can keeping live longer. It is better for Australian government to bring them here because they will get medication and all the assistance they need. If they left there in overseas maybe, they will kill themselves because there is no hope for their lives.

FGD3, Sudanese men

On the other hand, participants did acknowledge the public health and economic factors that influence Australia to pursue this policy.

Australian government have to protect their people, for if girl or man from Africa came here with HIV, he/she will transmitted that to others here in Australia... The Australian government wants to help refugees and helping her people too, they want to bring here healthier refugees or skilled migrants because they will work and increase Australian economy. Patients cannot work and cost government a lot of money for treatment, they will decrease the Australian economy.

FGD3, Sudanese men

The sympathy expressed for PLHA indicates the potential for social support for people affected by HIV/AIDS, if the fear within the community can be allayed. The participants' awareness of complex issues of migration and health economy again indicates the need to engage African communities in dialogue with health policy makers and health care providers in the ongoing development of Australia's response to HIV/AIDS, at both a local and possibly an international level.

1.2. Practices and behaviour

1.2.1. Protective behaviour

Abstinence from extramarital sex

The strategy most commonly described and promoted within African communities was abstinence from sexual activity other than that between husband and wife.

You know, because for Islamic people we don't do, have sex unless we get married. Before marriage, no sex. And even you know, the physical contact between woman and man are forbidden, so, you know, the, the first time to know about these things happened here in Australia, I never heard about it there in Sudan, and after of marriage this continues except maybe 99% of them they just

with their wives, and that's it, they don't have any sex out of their frame of marriage, so why they need to use condom?

SW11, Sudanese woman

This was the case in Muslim and Christian groups, and all ethnic groups studied. It was a view more strongly expressed by older members of the various communities. This was not the only strategy mentioned, but it was usually seen as the most socially desirable. However, leaving aside the obvious differences that exist in any society, between the ideal and the reality, the existence of many people in African communities who are widowed, separated and remarried, as well as the practice of marrying partners from abroad, expose the weaknesses in this strategy, even if its merit is accepted on principle.

HIV testing prior to marriage, although mentioned by several participants, is probably not being sought on a large scale in Australia, and is problematic to adopt as a public health policy (if it is suggested in contrast to testing in the context of relationships other than marriage). In addition, HIV-positive spouses of Australian residents are able to migrate to Australia, although the process is protracted. Marriages with partners from overseas are just as susceptible to breakdown as others, and this raises the possibility that known HIV-positive people may migrate to Australia and enter subsequent relationships after separation from sponsoring partners.

- Is there a... arranged marriages between home and, you know, overseas and here?

- Yeah, yeah, yeah... quite a lot.

K112, Young Eritrean man

Again, over-emphasising this uncommon scenario is not appropriate, but it does expose another weakness in the strategy of avoidance of extramarital sex as the mainstay of HIV prevention, without questioning the moral principles underlying the strategy. Given the strong link between religion, morality and social standing, it is important to find ways of developing effective HIV prevention strategies, as well as means of reducing the prejudice against people living with HIV/AIDS, that do not involve threatening core principles shared by the various communities.

Abstinence from sex with “high risk partners”

Another strategy adopted by African Australians to avoid HIV infection is avoidance of sex with people viewed as being at high risk of HIV. This approach is similar to that above, but does not include the moral or religious dimension, and was presented as an option by younger and older participants, of both religious and secular inclination.

If they want to use, if they will want to go to another, outside Dinka, you can get sexual diseases, different places, you can go with... you can use condom.

K117, Sudanese man

Categories of people viewed as “high risk” included: sexually promiscuous people, prostitutes, clients of prostitutes, injecting drug users, people from other ethnic groups, people of different religions, people living in Africa, and homosexuals. This classification was marked by the “othering” of risk, particularly where ethnicity and religion were concerned (see below).

Apart from the inaccuracy of such crude stereotypes in estimating actual risk of HIV infection, the strategy depends on full disclosure of an individual's personal history to a potential sexual partner, some aspects of which are stigmatised behaviours that are unlikely to be disclosed except to highly-trusted people. Some participants did acknowledge that some high-risk behaviour, such as injecting drug use, is sometimes difficult to determine before a sexual encounter.

Maybe you might see it after you do whatever, or the next day see her high like this, tripping on the street, but "Oh, I was with her yesterday! Damn, hell no!"
FGD9, Ethiopian young people

Use of condoms with "high risk partners"

Some participants indicated that they would use condoms with sexual partners who were at high risk of having HIV, such as prostitutes, and those whose risk was unknown, such as new sexual partners.

If you just met a person, you like them or not, you trusted them... it's the first day, you don't want to take a risk, often. After a while, you think about getting more... further relationship with them, maybe after that, you don't want to use it.
FGD9, Ethiopian young people

Some participants suggested that sexual contact with prostitutes was not uncommon among their social networks, and thought that condoms would be used in such encounters.

I don't know, I will feel more comfortable putting a condom on when I'm... maybe when I'm with a prostitute or something, rather than somebody you... you know.
FGD9, Ethiopian young people

Other "high risk" people would not generally be seen as desirable sexual partners. A concerning aspect of this strategy was the view that people would cease using condoms some time into a new relationship, but seeking HIV testing before ceasing to use condoms was not mentioned. This is an area that needs further investigation, because it seems that new sexual partners are later reclassified into a low risk group, but the basis of this reclassification does not necessarily include testing for HIV.

Avoidance of PLHA

Avoidance of any contact with known HIV-positive people was the other main strategy adopted for prevention of HIV infection among African communities. This involved avoiding any physical contact with an infected person, any sharing of household utensils, and minimising social interaction with HIV-positive people, even friends and family members infected with HIV. All contact is avoided because HIV/AIDS is viewed as highly contagious, leading to uncertainty about what contact might be "safe", and its image as an untreatable, fatal condition leads people to avoid even contacts that they have been told are low risk.

Personally I have concerns about HIV although I have worked with doctors and have some background education. For some reason I cannot help it, I think it can

be transmitted into any ways. I have heard and know, and many doctors told me that blood transfusion, uncleaned medical equipment can transmit the disease, also sharing of needles, unprotected intercourse can transmit the disease. However I still thought, God forbid, kissing of partner can be dangerous, saliva can transmitted. I have been told hundreds of times, and I read it in many places, but I cannot stop that thought in my mind that if a mosquito bit somebody who had the disease can be transmitted in that way. I am not sure. I have that concern.

FGD6, Somali women

The other reason for avoidance of PLHA, at variance with the fear of contagion through casual contact, is the assumption of sexual impropriety associated with HIV infection. In a sense, the presence of HIV infection identifies a person as an individual with whom one should not have social contact, who should be excluded from community activities.

The seniors people believe that the good Muslim will not get the disease, if somebody get the disease, they engaged in forbidden sexual activity, the disease attacks the promiscuous people that have no regular partners that sex free sex with unknown people.

FGD6, Somali women

This reason for avoidance of PLHA will not be addressed by education about the availability of treatment, and will only be addressed by education about transmission if that education is delivered with sensitivity and understanding of the social and moral context of HIV/AIDS and sexuality.

1.2.2. Behaviour towards PLHA

Avoidance

The behaviour most often described by participants in relation to known PLHA was avoidance of social and physical contact, both in Africa and Australia.

All people that love you... if there is someone who really loves you when they know you have AIDS and your body is finished, they abandon you, except for your mother and your sister and even your sister she will not stay by your side unless she has brave heart; but other people like your neighbours or anyone else they will never stay by your side.

FGD2, Sudanese women

Hostility and physical violence were described in Africa, but not in Australia. Support and care was rarely offered, except by health service providers in Africa and Australia.

1.3. Risk factors for HIV infection

Unprotected sex

The main risk factor for HIV infection among African communities in Victoria appears to be unprotected sex with partners who are viewed as “low-risk” but are in fact at risk of HIV infection.

Spouses, people who are not “promiscuous”, and people of the same ethnic group are perceived as low-risk for HIV infection.

To protect ourselves from HIV, we can use a condom during sexual relations with your girlfriend, for unmarried man or women. But for the wife you can't use a condom. If married couples have sexual relations outside of marriage, that is the dangerous thing to do. Both of the couple will be sick and die.

FGD5, Sudanese men

It [using condoms] made sense to me when I was back at home, but doesn't make sense to me, like... I don't know, it makes sense to some people, but it would not make sense to everyone, you understand what I mean? Like, what about people that are married? What about people that have... want to be proper, that don't sleep with prostitutes and stuff, you know?

FGD9, Ethiopian young people

... the youth themselves, they talk about, themselves. If they want to use, if they will want to go to another, outside Dinka, you can get sexual diseases, different places, you can go with... you can use condom. They talk, but we don't know [laughs].

KII7, Sudanese man

The problems with this way of thinking are self-evident: a spouse may have been married or had previous sexual contact before the current marriage; people do have extramarital sexual contacts; the shame associated with extramarital sex makes it difficult for a person to reveal such a history to their spouse; a spouse may have had non-sexual exposure to HIV infection (such as medical procedures or unscreened blood transfusion in a high-prevalence country), and be unaware that he or she is infected with HIV. Similar issues arise with sexual partners who are not seen as promiscuous, but whose actual HIV serostatus is not known. The sense of security associated with shared ethnicity means that stereotyped or idealised behaviour is attributed to the sexual partner that may have no relation to their actual life situation or history.

Most sexually active people in African communities are likely to be aware of the use of condoms to prevent sexually transmitted disease, including HIV. Although formal sexual health education in families is limited, public health messages and school-based sexual health education programs have a high degree of exposure in most of the countries or origin of these communities. Participants acknowledged the advisability of using condoms with sexual partners to prevent disease, but thought it preferable to dispense with condoms if the risk was low.

If you just met a person, you like them or not, you trusted them... it's the first day, you don't want to take a risk, often. After a while, you think about getting more... further relationship with them, maybe after that, you don't want to use it.

FGD9, Ethiopian young people

It would be beneficial to emphasise the impossibility of judging a potential sexual partner's likelihood of being infected with HIV, based on their ethnicity or assumed sexual history. This was ironically pointed out in one discussion:

"You are the one who killed me [laughing]." I am serious... because you cannot trust men. If you as a woman committed to your husband, men cannot commit and get into relationships and you never know what they are giving you.

FGD2, Sudanese women

Medical treatment abroad

Some members of African communities do go abroad to have medical treatment in the Middle East, but this is not common.

- *Do people go overseas from Australia for treatment specifically?*
- *Yes, Cairo, Germany.*
- *What sort of reasons?*
- *Mainly the language and the way they are treated. Australia is good, but to know my disease they take 6-7 months and the people cannot wait for this...*

KII9, Eritrean woman

Medical treatment abroad is more common when people resident in Australia become ill whilst travelling abroad. The risk of HIV infection through unsafe injections, surgery or blood transfusion is known within African communities.

...because you know there is a lot of blood transfusion there, in Sudan, but even in the recent year it start to, you know, test the blood and see ah... the people who donate blood, if they are HIV-positive or not. A lot of people, you know, just have this virus through a blood transfusion...through their medical instrument, or a surgery, in.. during a surgery, or during a visit to a dentist. Or even, you know, the vaccination.

KII3, Sudanese woman

Although this mode of exposure to HIV infection is unlikely to be of direct relevance to large numbers of people, it has important implications for community education about HIV transmission and attitudes toward PLHA (see below).

Injecting drug use

It appears that very few people from African communities are known to be engaging in injecting drug use, which is reassuring from a public health viewpoint.

...the some young people that arrived this country have started to use drugs, the majority of those to smoke marijuana. There are few that uses heroin to inject, but they are a very small minority in the community.

FGD6, Somali women

- *Like, you hardly find... how many junkies, black junkies, you'll find one in a million, you know?*
- *Four.*
- *Yeah, but, there's just the one... how many years he's been locked up. But, you know what I mean? But it's... And I don't know that... how many heroin users you know that have got HIV?*
- *There's not any African heroin users.*

FGD9, Ethiopian young people

However, the high levels of family disruption and numbers of disengaged young people within African communities indicate ongoing potential for the uptake of injecting drug use by African young people.

I heard about drugs but I did not see some using drugs. In our community now there is no one using the drugs but it will happen later on. If one of our communities got friends from white community who use drugs he/she will learn how to use drugs. Now our community is OK.

FGD3, Sudanese men

Some certainly have contact with social networks in which these drugs are used. One problem is the stigma associated with the use of injected drugs, among both older and younger members of African communities. This suggests that any African Australian young people who do inject drugs are very unlikely to reveal this to those of their peers from similar backgrounds.

- *Obviously, if someone wants to do something, they would not do it in front of people, they would do it alone, so that others cannot see them, but no one knows if there are people who inject drugs or not.*
- *But we did not see such a thing with our eyes.*
- *We did not hear anything like that.*

FGD2, Sudanese women

Any research, prevention and support programs addressing injected drugs among African young people will need to adopt approaches that are not limited to ethno-specific organizations.

Traditional practices

Traditional practices such as male and female circumcision, tattooing, scarring, and traditional surgical procedures are a potential risk for blood-borne spread of HIV infection in Africa, but these procedures are not being practised by African communities in Victoria.

[Female] Circumcision is prohibited. We don't use it here.

FGD6, Somali women

Some traditional healers are known to perform quite complex surgical procedures in Sudan, for example.

They got trained from family. They come from grandma, grandfather and grandmum. Yeah. They know how to fix... If you have broken your arm, or leg, they fix. They know how to fix it, yeah. Yeah, they open by knife, and take the... some... some bone out, and put another bone... yeah [laughs] and fix it. They know that.

KII7, Sudanese man

However this is another class of procedures whose practice is limited to Africa.

- ...are there any people here in Victoria, who have been trained in that kind of...?
 - No.
 - There's nobody came that can...?
 - Nobody can do that. Because those who have come here, most of them are young... Yeah. And if you are do this you are people is sixties and seventies. Yeah. Old people.
 - OK. So then they're not able... able to come.
 - Yeah. They don't want to come here.
- KII7, Sudanese man

People who have undergone some of these procedures prior to their migration to Australia have had to pass the migration health requirement. The implications for the existence of HIV-infected people among the African communities in Victoria are similar for sexual and blood-borne risk groups. That is, people aged 15 years and over at the time of application for a visa would have been tested for HIV infection some weeks to months before travel. This suggests that, theoretically, some children who have been either circumcised or had other procedures may have been exposed to HIV infection prior to migration, yet not have been screened for HIV. It is impossible to estimate the number of people who might fall into this category, without detailed knowledge of the rates of practice for these procedures among the populations from whom visa applications are made.

Like medical misadventure abroad, the existence of this category of risk for HIV infection in Africa also implies that it is not possible to know the means by which an individual African Australian person who is diagnosed with HIV acquired the infection. Although it would be wrong to over-emphasise the importance of blood-borne transmission in Africa, it is worth mentioning in public health education for two reasons: firstly, it underlines the importance of practising safe sex with any person whose serostatus is not known, not only those seen to be at high risk of sexual acquisition of HIV; secondly, it may reduce the stigma associated with HIV infection among African communities, if it is understood that infection with HIV does not automatically indicate sexual immorality by the standards of the community.

... the first thing would be, unfortunately you know, would be, whether they've had safe sex or heterosexual relationship, or something like that, or a same sex relationship. They won't think that it's from you know, blood transfer or victim of medical hiccups or something like that, no. The first instance would be is, it's very much related to us to unsafe sex.

SWI10, Sudanese social service provider

1.4. Awareness and concern about HIV/AIDS and STI

We attempted to assess the level of awareness of HIV/AIDS as an issue affecting African communities in Victoria, and the perception of a need to act on the issue.

Lack of previous discussion

Within African communities, there has been very little discussion about HIV/AIDS in Victoria to date. Many participants said that the interview was the first time they had talked about this issue in Australia.

... since I come to Australia, I didn't heard from any services about talking about HIV. The community centres or different places of the health. Nothing information about it.

SWI13, Sudanese woman

They recalled little or no public health information or media attention paid to the subject of HIV/AIDS as it relates to Australia's African communities. Within English language schools for recent immigrants, some health education sessions have been conducted that do address HIV/AIDS, STI and sexual health, but this has been done without extensive discussion with African communities, partly due to fear that some community leaders would not support discussion with young people of issues pertaining to sexuality.

There's a lot of... or there is some controversy here, which hasn't boiled out into the... so we presume they don't...the parents don't know we're doing this, yeah.

KII5, Health services provider

In view of the support given to the current research project, such fears may not be totally justified. African community leaders, once they became aware of the importance of HIV/AIDS to their local communities, were very willing to enter discussions and offer practical assistance in the development and execution of this project.

Unaware of AIDS in Australia

Most participants reported that the community perception of Australia was that of a country where HIV/AIDS is very uncommon, or may not even be present.

You know, like... it's hectic down there, as far as I know... Only people talk about... when it comes to HIV, it's all back at home. I mean, I know there's heaps back at home, but I don't know if there's any down here...

FGD9, Ethiopian young people

They can see on the TV, you know... Africa, AIDS, you know... is rising, you know... the Nigeria is going up... And India, they send for drug, for inappropriate or... But they not aware of, in Australia... They always see for... in Africa.

KII6, Somali man

This perception that there is no HIV/AIDS in Australia is an influence on the behaviour of people who try to avoid sexual exposure to HIV infection by using condoms during sexual contact with "high risk" partners. Since there is already a willingness to adopt the use of condoms if they are seen to be necessary, a more realistic awareness of the HIV/AIDS situation in Australia has the potential to have a significant impact on rates of unprotected sex.

Unaware of HIV/AIDS in African communities

Where African communities are aware of HIV/AIDS in Australia, few people are aware of HIV-positive African immigrants in Australia. Of the participants in the research, only those working as health service providers knew of African Australians with HIV/AIDS.

there is a rare number of infected people in our community, and no-one know about them,

KII3, Sudanese health services provider

Like the perception of HIV/AIDS in Australia as a whole, the perception of HIV/AIDS in African communities seems to be influential in the adoption of safer sex practices by members of Victoria's African communities. Again, a possible response is to provide more realistic information about the existence of HIV/AIDS in these communities, as among other groups in Australia.

“Othering” of risk

When describing people who would be at risk of HIV infection, participants generally mentioned people who differed from them in some way.

Because they think to themselves as far away of having this, of getting this virus.

KII3, Sudanese health service provider

Where the distinction was made on ethnic grounds, the ethnic group of the participant was described as being at lower risk than others.

When I came here in Australia I met you [community leader] and learned that there are no sick people with this disease in our community.

FGD3, Sudanese men

So the rate of HIV when you go to Ethiopia, is very high compared to other countries like Somalia.

KII19, Somali man

No AIDS in Dinka.

KII7, Sudanese man

When the distinction was religion, the religion of the participant was described as protective, compared to other religions.

But the number of people who are HIV carriers is very limited in the Horn of Africa community, particularly the Muslim community (Somali and Eritrean community), mainly because their sexual relations with others (Muslims) is limited, so spread of disease is very limited. 5 years ago a report from the UN said that Somalia had the lowest HIV infection rate in Africa, and praised it, saying that this was partly due to the religion. In the religion, there is no sex outside marriage, and homosexuality is zero.

KII26, Somali man

Older people tended to view young people as being at higher risk than themselves.

Young man and girls are the problems now. The question is: how to help them? Because they have been affected by open sexual relation.

FGD3, Sudanese men

This “othering” of risk is a recurring theme for sexually transmissible diseases worldwide throughout history. When combined with protective strategies that depend on classifying potential partners according to risk level, means that people are unlikely to classify individuals as “high risk” if they are similar to themselves. However, the overlapping diversities of ethnicity, language, religion, age, gender and social networks enable almost any person to be “similar” or “different” according to the criteria of classification. In addition, none of these markers of distinction enable accurate prediction of HIV serostatus; any intervention that involves the use of condoms, for example, must emphasise the need to use condoms in all sexual contacts where the HIV serostatus of one partner is not known (that is, almost all sexual contacts, in the first instance), rather than selectively using them for “high risk” partners.

2. Barriers to timely diagnosis and optimal treatment

2.1. Timely diagnosis

Timely diagnosis of symptomatic HIV infection depends partly on people seeking screening HIV testing. Three factors seemed to contribute to delayed diagnosis of HIV infection among African communities by lessening the likelihood of self-referral for screening: low self-perceived risk; competing priorities of migration and settlement; and fear of a diagnosis of HIV infection.

Self-perceived risk

Most people in African communities are unlikely to view themselves as being at risk of HIV infection. The experience of HIV screening prior to migration and the belief that HIV is uncommon in Australia (particularly in African communities), lead to the view that contact (sexual or otherwise) with HIV-positive people is unlikely to occur in Australia.

The other point, the refugees screened and negative, sound like confident they don't protect until they come.

FGD1, Ethiopian men and women

... all the people to enter Australia they have to do the test for AIDS, and once they're here they're safe.

SWI5, Sudanese woman

It is important to address the issue of self perceived risk of HIV exposure, as this is one way of encouraging asymptotically infected people to seek testing for HIV. This has benefits for the individual, who is diagnosed before the onset of severe symptoms, and also for the community, as HIV-infected individuals are given the opportunity to modify behaviour that may place others at risk of exposure, and, if treated, become less likely to transmit the virus during situations of potential risk, such as pregnancy, childbirth and breastfeeding.

Competing needs of migration and settlement

The period after migration to Australia is busy, with competing priorities of accommodation, employment, education and immigration other family members. Health in general tends to be assigned a lower priority than these other matters, and sexual health or HIV/AIDS is far from being the major concern of most African immigrants.

... choosing the right time is very important, I mean you can't talk to them about this issue once they arrive in settlement or else you won't get their full attention.

SWI10, Sudanese social services provider

Awareness of competing demands on the time of recently arrived immigrants is essential if HIV-related education materials are to reach the appropriate audience, in a setting in which they are receptive to the information. This is an issue facing health care providers to refugees and immigrants in general, and is being addressed as part of the

overall approach to refugee and immigrant health care. HIV/AIDS is an important issue, but it is one of many.

Fear of diagnosis

With the knowledge of the physical effects of HIV/AIDS in the African context, and the awareness of stigmatisation and isolation of people identified as HIV-positive, and a limited awareness of the availability of effective treatment, the diagnosis of HIV infection is not seen to be an overall benefit by some people in African communities. The benefit of diagnosis was seen to lie for the most part in the ability of a HIV-positive person to protect their friends and family from contagion.

Imagine for example, you have... you not gonna act like you did before. You will change, you know, you will have a lot of stress, you won't be happy, you know? So it's better like, you don't know. Just leave it go.

FGD9, Ethiopian young people

It's for the benefit of other people, more like... when I say "other people", not "everyone" other people, more like, more my family, you understand what I mean?

FGD9, Ethiopian young people

If people are to seek screening or diagnostic testing for HIV infection, they must know that some benefit will follow from the diagnosis.

2.2. Optimal treatment

Stigma

Stigma and fear of disclosure may limit access to HIV-specific services, or even infectious diseases clinics where HIV-positive patients are known to receive treatment. There is a chance that a patient may be seen attending a clinic by members of their community, from whence rumours may spread.

*When I, oh... I went to... with the client to... like, infectious disease department, or something like this, I just worried if someone of the Sudanese community (laughs) see me here. Because they go, "Oh, I saw ** in there, maybe she is infected with..." And I start to... but, I don't know... what can you do? (Laughs).*

KII3, Sudanese health service provider

Addressing this situation ultimately depends on reducing the stigma associated with HIV/AIDS in African communities, but in the short term, measures should be taken to reduce the need to attend services "labelled" as HIV/AIDS-related, and to wait for long periods in publicly visible areas that are associated with HIV/AIDS services.

Confidentiality

The concern with maintaining confidentiality of personal information is the major concern for African PLHA. This may affect their ability to attend clinics (see above). It

may also affect their readiness to divulge information to health care workers; trust in the beneficence and confidentiality of professional health workers may not be automatic.

They will not, never, never, from the first time, is he going to trust you. So it is a matter of time. It's a matter of many meetings, many contacts with them... yeah.

KII3, Sudanese health services provider

This may be due to experiences or knowledge of situations in Africa or Australia where health workers either divulged information pertaining to clients, or themselves harmed clients or patients under their care. Concerns about confidentiality also affect the readiness to use interpreter services.

Confidentiality is questioned culturally. There is no perception that the interpreter has rules to obey, or is under obligation not to expose the secrets of others. They don't believe that what happens in the clinic stays in the clinic.

KII26, Somali man

Many African immigrants to Australia are not fluent in English. Even adequate fluency in conversational English may not be adequate when it comes to the more specialised vocabulary of health care workers.

... sometimes it's not enough you speak English. The language around hospital is different. And people say, "Say it in English!" Because that's you know, you are "Gastro", stuff and stuff which we never heard of. Yeah. It doesn't matter you speak English or not, you need someone who make clear understanding, what's going on.

KII18, Young Ethiopian woman

In addition, literacy may not be high, either in English or in other languages, even those spoken fluently.

In many cases, an interpreter is needed for good communication in health care settings, and the use of professionally trained interpreters is preferable to the use of family or friends, both for privacy over sensitive health issues, and for technical competence in interpreting. However, in the area of HIV/AIDS, the priority of patients/clients is often to maintain confidentiality and particularly to avoid disclosure of their diagnosis to members of their own community. African Australians with HIV/AIDS may thus refuse to use interpreters from their own community, and even family or friends may not be used. This presents a major difficulty for the full discussion of the complex issues to be dealt with in the management of the physical and psychosocial aspects of HIV/AIDS.

There is little confidence in the professional maintenance of client confidentiality by interpreters. There is also a lack of interpreters, particularly for languages of very new groups of immigrants, and those spoken by very small communities.

... it is hard, some tribes of Sudan doesn't have translators, and they can just use friends or family members.

SWI7, Sudanese woman

The actual professionalism of interpreters may vary, but importantly, there is no widespread understanding or confidence in this professionalism among the communities. Development of sufficiently numerous and capable interpreter services,

with adequate support and supervision is necessary to deliver adequate service for communities and health workers. However, some effort should be directed to development of a professional structure and maintenance of professional standards and importantly, to making the existence of these known to the various communities.

[Note: One objective of this study was to assess the physical and psychosocial burden of illness for African Australian PLHA. The case series will address this research objective, but the secondary reports from participants in the community study (particularly health service providers) have shed some light on the psychosocial aspects of living with HIV/AIDS in Victoria's African communities. The major themes concern stigma, concern for confidentiality, and the social isolation due to avoidance of PLHA by their communities. These themes are discussed in more detail below.]

3. Health workers perspective on HIV/AIDS in African communities

Health workers have an important perspective on the issue of HIV/AIDS in the African communities of Victoria. Relevant groups include infectious diseases physicians, general practitioners, refugee health nurses, immigration medical and nursing practitioners, HIV bicultural support workers, to name a few.

In this study we include data from practitioners working in the areas of HIV support, immigration health assessments, and refugee health.

3.1. Immigration

As mentioned above, applicants for temporary or permanent residence in Australia must pass a health requirement in order to succeed in their application. In many cases this involves a screening test for HIV antibodies. HIV testing is required for all permanent residence applicants aged 15 years and over, and children who are prospective adoptees, as well as others who have specific risk factors for HIV (at the discretion of the medical officer making the assessment). Temporary residence applicants who are intending to study or work in medical or dental fields must also have an HIV test.

Frequency of diagnosis during screening

The number or proportion of applicants for residence in Australia who fail due to HIV diagnosis is not known; nor is the number of HIV-positive people who are eventually able to settle in Australia by granting of a waiver of the health requirement. However, during health screening of on-shore applicants for residence in Victoria, 1 or 2 positive HIV screening results are received each fortnight. The proportion of African-born people among this group is not available. Medical assessment for the health requirement is undertaken by Health Services Australia, a Commonwealth business enterprise. HSA nurses carry out screening and pre-test counselling. The results are reviewed by one of the Medical Officers of the Commonwealth employed by HSA for this purpose.

Statistics have been requested from DIMA about the number of residence visa applications granted and refused on the basis of health requirement and HIV testing.

Follow up of positive diagnosis

If an applicant for a residence visa is found to have HIV during the screening for the visa health requirement, he or she is contacted by the Medical Officer of the Commonwealth, told that there is a problem with the medical assessment results, and offered a consultation with the MOC. The MOC involves the contact tracers of the Department of human Services Blood Borne Viruses section, who are present when the diagnosis of HIV infection is given to the applicant, and assist with post-test counselling. In Victoria, the applicant is referred to the Melbourne Sexual Health Centre for follow-up. HSA notifies positive results of HIV screening to the Victorian HIV Registry, but is not involved in the further medical follow-up of the applicant.

K111, health service provider

Understanding of process of exclusion

HIV-positive applicants fail the health requirement. The reason for rejection is cost of treatment. The lifetime cost of HIV to the Australian health system is \$250 000, regardless of the stage of HIV illness. K111 is uncertain of the origin of the figure quoted for cost of HIV treatment. She thinks that the head doctor of HSA may know.

If an applicant has an employer-sponsored work visa (which may be for several years), a health waiver can be obtained from DIMIA. This is not carried out by HSA. This occurs infrequently – K111 recalls only 1 or 2 cases in the 1 year that she has held her current position.

K111, health services provider

All visa applicants with HIV fail the health requirement on the grounds that HIV is a disease that poses a significant cost to the Australian health care system. It is possible for applicants to appeal the decision, and some are able to have the health requirement waived, and can settle in Australia. However, the MOC is not involved in this part of the process. There seems to be a lack detailed understanding among health and immigration service providers, as well as the African communities, about the process by which Australia accepts some HIV-positive people to settle, but rejects others. Certainly, impression in the African communities is that no HIV-positive applicants are allowed to settle in Australia, but that is not correct.

In this country, when you are coming from that... want to enter to Australia, they make check up... a medical check up. If they got the AIDS problem, they don't allow you to come in. Yeah. And we know everyone here, we going to have the same thing. Yeah. But we hear from the embassy in that place, anyone who have the disease like AIDS, will not allow them to go in.

K117, Sudanese man

As detailed above, the perception of African communities is that Australia's African communities are essentially free of HIV/AIDS. It should also be noted that health workers who are aware of the migration process may also reach similar conclusions. This may affect their decisions when considering diagnostic tests.

3.2. Refugee health

Perceived need for information

Refugee health service providers recognise that recent immigrants from Africa need to know about HIV transmission, prevention and sexual health. They report a wide spectrum of existing knowledge, ranging from very little accurate knowledge, to a good understanding of contraception and STI prevention.

...some who know the issue are very aware of the issue, but some are very confused as to what... you know, HIV is, or how you can contract the disease, and things like that.

KII5, Health service provider

As a response to this situation, several health organisations such as suburban clinics are beginning to provide education to newly arrived refugees about sexual health. However, this initiative has faced some problems.

Difficulties providing sexual health information

Refugee health service providers have several difficulties in providing information to newly arrived refugees about sexual health.

Firstly, not all refugees access health services.

Some time ago, when I walked in Footscray, I knew almost every Sudanese I saw, but this time I don't... I'd walk and I don't know anybody. And then I presume all of those I haven't met before haven't been screened, so yeah, you see the need is big... yeah.

KII5, Health service provider

Interpreters may feel uncomfortable with the subject matter of sexual health.

...it's the... the adult workers who feel uncomfortable, but the kids are happy to... for us to talk to them about this.

KII5, health service provider

Communities may disapprove of the teaching of sexual health to young people.

See, what we know is that the Sudanese are sending their kids to the Catholic schools because they don't want them to be exposed to... the sort of things we do, you know, like to... that kind of sexual health thing, and... condoms, and things... from the teachers' experiences, you know, the welfare officer and the others, they think... if this gets out into the community, it might not be received very well. Yeah.

KII5, health service provider

This “covert” approach may be sufficient as an interim measure, but has the potential to cause needless strife between communities and service providers.

Concern about unwanted pregnancies

Refugee health workers and other service providers are concerned about a recent spate of unwanted pregnancies among young girls from African refugee backgrounds.

... we've had a... say, an epidemic of teenage pregnancies, yeah, towards the end of... say all of last year.

KII5, health service provider

Some of these young girls did receive sexual health education in their English language classes after migration, but the circumstances leading to this situation need further investigation.

... at least about three of the girls last year, yeah, we knew... they have come from the language school, and then we've... they would have, um... been in one of our classes... so... we're not doing something right...

KII5, Health service provider

Regarding HIV/AIDS, this is an indicator of unprotected sex among young people, and thus of risk of STI and HIV infection. It also indicates the need for evaluation of the delivery and impact of sexual health education of refugee young people.

3.3. HIV support workers

Several HIV/AIDS services have recently begun employing men and women from a number of CALD backgrounds as bicultural support workers for PLHA from CALD backgrounds. They are trained and employed to offer emotional support to PLHA and assist them in accessing various services.

Establishing trust

The most important task for the HIV support workers is to establish trust between themselves and their clients. The experience and fear of stigma and social isolation means that PLHA from African communities are very reluctant to trust health workers, and may be reluctant to meet with them to begin with.

... the match is difficult, sometimes... for especially African communities, to match a worker and, for example, you see Sudanese woman or man been infected, ah... from the beginning, to convince him to reach these service, and you know, to agree to have these services is really difficult... from his own community, it is the most difficult thing for them: "Oh, the support workers is Sudanese, that means I'm going... and tomorrow the whole community they gonna know that I'm HIV positive." So, it is a little bit hard.

KII3, Sudanese health services provider

Once the relationship is established, clients may slowly begin to disclose information.

From the beginning you should have to deal with him carefully, until you get enough trust with them. So, after that, you... it's step by step... until you reach end

point... having a good communication, with them, and you can help them as long as they need, after that.

KII3, Sudanese health services provider

Maintaining confidentiality

The next most important task of HIV support workers is to maintain confidentiality and protect the privacy of their clients. This must be done even where there are conflicting social and professional obligations within a small community.

I was living in dilemma of not being able to disclose that information to the community, because of professional confidentiality and on the other hand this person may transmitted the disease to other people. So I don't know what to do. That person is married and I am not sure whether he told his wife he was sick or not, should I talk to him or asked his wife, I shouldn't.

FGD6, Somali women

The maintenance of confidentiality is central to the ability of support workers to enjoy the trust of their clients, who are then able to share their concerns.

When communicating with other health workers in a team, HIV support workers and others must remain conscious that what they see as normal professional communication between team members may in some cases be viewed by clients as a breach of privacy.

...they just start to test you with informations, they tell you something, if the supervisor came and... already...came... came and talk in the same issue with them, that means, "Oh, he go and talk with the supervisor, so he can talk to anyone else."

KII3, Sudanese health service provider

Clearly, the experience and perspective of the bicultural support worker has the potential to improve the accessibility and acceptability of HIV/AIDS services for their CALD clients. Such experience may also be of use in settings other than HIV/AIDS.

Client disbelief of diagnosis

One challenge for HIV support workers is the disbelief of clients in their diagnosis of HIV. It may be difficult to provide “evidence” of HIV infection that satisfies the client or is consistent with the client’s previous understanding of HIV/AIDS. On the other hand, support workers may be better-placed than other health workers to discover the existence of such fundamental misunderstandings between health service providers and clients.

... we start to talk with him, and... the important thing for him is to tell us that... he doesn't have AIDS. He is not positive... "Why they let me come in Australia if I'm... no-one can come here if they are infected." And it is really a matter of, like they don't know about information about HIV, and... how long it takes to appear in your blood, and the test being positive. And if you have the virus in your blood, you may not have the symptoms of the virus for a long time, maybe fifteen or twenty years. So, they don't... you can... it is not hundred percent if you have a... a

child... or you are pregnant that the child is going to be positive. So, I think it is like, they don't got the enough information about HIV so, why they are not convinced.

KII3, Sudanese health service provider

Like the African communities in general, PLHA from African backgrounds may have been exposed to a great deal of information about HIV/AIDS in the African context, and little in the Australian context. Medical and other health practitioners need to be aware of this pre-existing knowledge when communicating with their patients and clients. The bicultural workers play a role in uncovering hidden areas of misunderstanding between the therapeutic partners, but can also assist in capacity-building of HIV/AIDS services, by educating and training their staff about such issues.

Lack of mutual client support

Although there are a number of African people living with HIV in Victoria, concerns of privacy mean that they are not willing to form mutual peer support groups with each other, or with existing peer support groups.

- ... do any of them know about other... other people from the community with HIV, or each person is... all they know about is themselves?

- No... No. They don't even talk about it...

KII3, Sudanese health service provider

This area is one of the most sensitive for PLHA. On the one hand, the perspective of other people who are dealing with similar issues may help an individual to deal with their own problems living with HIV/AIDS in African communities. On the other hand, there is the fear of unwanted disclosure to the community. There are other potential barriers to African Australian PLHA accessing peer support groups. These will be explored in the case series, with people who are making use of these groups, and those who presently are not.

4. Means to discuss HIV/AIDS and STI with African communities

This question addressed the provision of HIV/AIDS-related information to African communities. We examined the sources and impact of past and current information, and asked about potentially effective sources of information for the future. We also asked about issues that should be considered in the development and delivery of such information to the communities.

4.1. Current sources of information

African communities already have extensive and complex understanding of HIV/AIDS in the African context. This existing knowledge and understanding is sometimes not applicable to the Australian context, but it must be taken into account when developing community education initiatives concerning HIV/AIDS.

... not confused, but they didn't really understand the modes of transmission, or... and some of the myths, you know, like... say, the classic one was, oh, if somebody had HIV or AIDS, you could tell, because they would be skinny and unwell, you

know, looking, yeah. Yeah, so those are some of the misconceptions we have to... try and, yeah... correct.

KII5, Health service provider

This illustrates the gap between perceptions of health workers and communities. The question arises of what constitutes knowledge and authority. The credibility of sources may depend on the manner in which knowledge was acquired (personal experience, scientific research, formal teaching or informal discussion), and how it impacts on other areas of knowledge, experience and values.

Personal experience

Many members of African communities have had personal experience of the effects of HIV/AIDS on their families, friends and communities, in their countries of origin, or during transit to Australia through other countries.

I have seen the death of AIDS in Sudan; it is very difficult.

FGD2, Sudanese women

... there's two ladies that I knew that had HIV when I was back at home that died, and that... you know... They were next-door neighbours, and shit.

FGD9, Ethiopian young people

I saw a woman, used to be my friend; she was very beautiful... I saw a woman, used to be my friend, used to come to my house very often; she then got separated from her husband and moved to live with me; she used to go to wash [work in a laundry] and come to sleep at my house; then she moved to a place call "Al Hofar." After several months she got sick; I was not able to go and see her, because I was busy with my work at a restaurant; they told me she was about to die. I saw her at the hospital; she was lying on the floor. I was not able to look at her; after she died they told me she was very thin; she used to be very beautiful; she is from Dinka tribe.

FGD2, Sudanese woman

The experience of HIV/AIDS in Africa contrasts with the lack of such experience in Australia; the small number of affected people and the secrecy that surrounds them, mean that African Australians do not observe the effects of HIV/AIDS in a country where treatment and health support services are available.

African immigrants are likely to have had more direct personal experience of HIV/AIDS, and sometimes more formal teaching, than many of the health care workers and public health educators who are trying to inform them. It is important to take this into account when planning and assessing the effects of community education in Australia.

Media and public health information in Africa

Many people who have migrated from Africa have been exposed to large quantities of information about HIV/AIDS in media and public health campaigns.

- *Did hear about this disease before coming to this country or after you arrival?*
- *No, before coming to this country, when I was in Nairobi area in the refugee camp.*

KII11, Ethiopian (Oromo) man

About HIV or AIDS? I think back home it's everywhere on the news, or on the daily paper, and maybe on TV, they teach a lot, they... yeah. They teach a lot.

KII18, Young Ethiopian woman

- *... in school, I learnt about it.*
- *So in school in Egypt.*
- *Yeah*

KII28, Egyptian man

Even in countries like Sudan, where public/media discussion of sexuality was previously very limited, the importance of HIV/AIDS has led to increasing levels of publicly available information on this issue.

But I think now when the disease become.... become how I say, too much, the government they didn't find any way to hide this information, yes they have to talk to the people, yes, because lots of people have AIDS now in Sudan, even in the capital of Sudan and everywhere.

SWI5, Sudanese woman

This contrasts with the little information about HIV/AIDS that Africa Australians see in the Australian media, and the small quantity of public health information that they receive about HIV/AIDS in this country. Where information is seen in Australia (particularly in the media), it tends to concentrate on the situation overseas, particularly in Africa.

I... since I come to Australia, I didn't heard from any services about talking about HIV. The community centres or different places of the health. Nothing information about it.

SWI13, Sudanese woman

- *And what about when people come here? Where do they hear about it here?*
- *Oh, not much. Not much.*

KII18, Young Ethiopian woman

Migration health check

Most adult immigrants from Africa have experienced the HIV screening test as part of their health assessment prior to travel to Australia. Those too young to have been tested at the time of migration may know of the test through the experience of others in their family and community who have migrated to Australia at an older age. This shared experience has left a significant impression on the perception of HIV/AIDS in Australia, and specifically to the perception that there is little or no HIV/AIDS within their own communities who have been through this screening process.

I take it, since long time ago, when I got to Cyprus I had to... have to do the HIV test and a negative that and stuff, so I have a confidence I'm... I don't have that virus and... but in other way, you don't know how you been infected by that... by the virus, because it has too many ways and... you know?

KII18, Young Ethiopian woman

- ... there was a person among our youth who was identified as being infected with this disease while he was under going a medical examination to go abroad and rejected.

- This is for resettlement to a third country of asylum.

- Yes, this was aimed at going abroad and he missed that opportunity as the person was diagnosed.

KII11, Ethiopian (Oromo) man

- Does HIV screen affect your view?

- There is a big difference in my understanding of HIV. When I was doing the healthy examination process I thought it was a generally healthy examination of diseases but now I became more alert.

- In my view it is a good idea to be tested before arrival, if you have the disease you will contact the doctors and you start treatments, if you do not have, you feel happiness, healthy and safety.

- I thought why you need to be screened this disease? The disease can be communicated into many ways, when we were in our country we believe that the disease is communicated into intercourse and if the woman is not promiscuous she will not get the disease, but now I am aware that it can be get through blood transfusion and other ways.

FGD6, Somali women

... all the people to enter Australia they have to do the test for AIDS, and once they're here they're safe.

SWI5, Sudanese woman

However, the time between the medical assessment (including HIV screening) and travel to Australia can amount to several months.

- ...can you recall what the time was between having the health check and leaving Yemen?

- It was, ah, supposed to be less than 6 months, but because of the air fees to have your ticket, it's from you, that's the thing that made it long, because you want to... to prepare the ticket...

- Because you need to get them , buy the ticket...

- ... the ticket, yeah

- So that obviously was longer than 6 months, would it have been between 6 months and 12 months or less than that?

- 7 months.

SWI14, Sudanese woman

This indicates that the pre-migration HIV screen does not exclude infection among immigrants. There is a window period after recent infection, when HIV antibody testing is equivocal or negative; there is also time between screening and travel where new infection can be acquired.

... there is a period when the... from being infected with the virus until it really in your blood, so, it takes like six months, so some of them, you know? The gap is enough for them to come here, to Australia, and they just start to have pains, and so... you know, simple symptoms, and went to the hospital, and then discovered themselves HIV-positive.

KII3, Sudanese health service provider

From this account, which is not unusual, it can be seen that the existence of the HIV screening policy does not exclude HIV infection among groups or individuals arriving as immigrants to Australia.

Media in Australia

The participants in this study said that little Australian media attention had been given to HIV/AIDS, and that which was given dealt mainly with HIV/AIDS in Africa.

They can see on the TV, you know... Africa, AIDS, you know... is rising, you know... the Nigeria is going up... And India, they send for drug, for inappropriate or... But they not aware of, in Australia... They always see for... in Africa.

KII6, Somali man

Australian media, when mentioning HIV/AIDS in Australia, focus more on the rare event of infection via blood transfusion or medical mishap.

And you know the press and the media talk in everything, they just put, AIDS, AIDS, AIDS everywhere. You'll still be worried about your health here in Australia, although there is a lot of precautions, a lot of procedures to prevent you from getting.

SWI1, Sudanese woman

The impact of the Australian media treatment of HIV/AIDS on the views of African communities is to move the focus of attention away from communities in Australia, and away from the important means of transmission in the local setting. The magnitude of this impact cannot be assessed from the current study, but it is worth further investigation, partly to understand the scale of the potential problem but also to judge the effectiveness of the mainstream media for HIV/AIDS education for CALD communities.

Community discussion

Community discussion groups in Africa had been a major source of information for African immigrants prior to their arrival in Australia, and such discussion groups are a popular and well-accepted means of community health education in Australia. However no health education discussions have as yet dealt with HIV/AIDS in African communities in Victoria.

“You know, like... it's hectic down there, as far as I know... Only people talk about... when it comes to HIV, it's all back at home. I mean, I know there's heaps back at home, but I don't know if there's any down here... you know... It's my first time talking about HIV.

FGD9, Ethiopian young people

Thus, current discussions within African communities serve to reinforce the perception that HIV/AIDS is not a local issue.

Health workers

Health workers, particularly doctors, were viewed as a reliable source of information about HIV/AIDS, but most participants felt that African Australians would only seek information on this topic from doctors if it directly concerned them – that is, they or a family member were infected.

The problems is that I am not concerned about this disease because no one I know is affected by it so it is of low priority for me to go to the doctor and ask about it.

KII31, Egyptian woman

Health workers are probably under-utilised as a current source of information about HIV/AIDS, but are well-placed to provide such information, as they are seen as credible sources, and are relatively accessible.

4.2. Preferred sources of information

Participants were asked to suggest methods for providing African communities with information about HIV/AIDS.

Community discussion

Community discussion groups were the most popular suggested method of delivering health information. Such groups are already an established means for providing various kinds of information to the communities; the groups are in existence, and invite speakers to talk with the members and answer questions. Many different groups exist, according to various overlapping ethnic, language, geographical, age, gender and social distinctions.

To have bilingual workers, to hold health information conferences and seminars, to divide people into groups like young people, middle aged people, parents. To train professional.

FGD6, Somali women

And even they like the one, or the speaker who can attract them to... who can, you know... like, bring someone who have AIDS, and let him talk to those people about his experience. This, you know... this is more interesting for them.

KII3, Sudanese health services provider

This method has several advantages. It uses an existing structure; it allows dynamic interaction and rapid clarification of misunderstandings. However, personal concerns

are not easily aired in a group setting, and some more contentious topics may prove divisive.

Health workers

Health workers, such as doctors, are viewed as sources of reliable information about HIV/AIDS, but more for those affected by the conditions than those wishing to know about its transmission or treatment in general.

- And you think on a topic like HIV, they would probably rather talk to providers rather than their friends?

- Yeah, as I said to you, if someone is infected by HIV they don't even want anyone to know about this.

SW11, Sudanese health service provider

I wouldn't go to a doctor to find out stuff generally about AIDS. I suppose if for what ever reason I happen to have the disease or the infection then I would consult a doctor, if a good friend of mine had it, but I would just visit the doctor about AIDS, if I wanted to know general stuff about it, I would probably just search the net.

KII27, Young Egyptian woman

The problem with the current situation is that people tend to discuss issues of immediate personal concern with their doctors. Where the individual does not perceive the relevance of the issue, it is left to the doctor (or other health worker) to raise the issue, and explain its relevance to the patient/client.

Media

Ethnic media were mentioned as potential sources of information for some communities. Specific media referred to include: Somali radio; Arabic radio; Arabic newspapers; Horn of Africa newspaper (The Ambassador); Arabic satellite TV.

... you can go through radio which is, I think, the most effective way of educating the Somali community, so through the radio to give a wide information about that.

KII8, Somali woman

... if we got like you know TV or channels that can speak the language, your language, people will start, because people really some of the Sudanese now bring into their homes satellite to see Sudanese channel or Arabian channels, cause they do understand them. You can reach them.

SW11, Sudanese health service provider

Other media, directed towards the general population, were also suggested.

... if there is information even delivered through the post, such as all the junk mail we get daily about all sorts of stuff, we always look through it even though it is junk mail. Included could be an information pamphlet about AIDS, translated in several languages, just a few lines about the disease and how you get it etc etc.

You know like the water shortage, there is heaps of advertising on it and since this people now actually are a bit more conservative with water and will only use it when needed. Similarly we can get some form of advertising through mail or TV about AIDS disease. Everyone will read it or see it on TV. This way people will learn.

KII31, Egyptian woman

The limitations of ethnic media are resources and audience size. Although use of ethnic media immediately highlights the topic of discussion as one of interest to the audience, the diversity of African communities, and the changing use of languages among generations, mean that reaching a mass audience is likely to depend on use of mass media, with the attendant expense. This may prove justifiable, however, as African communities represent only one group of CALD communities in Australia, and the global trends in HIV epidemiology will make it a topic of increasing relevance to Australian society as a whole.

4.3. Issues in delivering information

Participants were asked to identify issues that need to be considered when developing and delivering information material about HIV/AIDS to African communities.

Language

Most participants mentioned the importance of delivering information in a language spoken or read by the audience. Verbal information in English was thought appropriate for young people, but for older community members, presentation of verbal or written information in their own language was seen as a way of engaging interest in the subject matter, highlighting its relevance to the particular audience, and ensuring understanding.

... it's the education information sessions the best things. With the native speaker, who can speak the same language. And just simplify the information as well. To use the movies, something like visual... visualising the information, more than just speaking or talking. They get bored easily. My people get bored easily.

KII3, Sudanese health services provider

Because the translated information is set aside, and later is put to rubbish. There are some people who cannot read Somali language and English language, it will be more effective to recruit bilingual workers to educate community.

FGD6, Somali women

This highlights the need for multiple approaches to community education about HIV/AIDS. It is important to use languages that are understood by the intended audiences, and materials are best developed by native speakers of languages, rather than translation of English materials into languages where meaning and implications may subtly change.

Age and gender separation

Most communities traditionally avoided discussion of sexuality between males and females, except between marriage partners. Therefore verbal or publicly delivered information needs to be given to a single-sex audience in most cases, in order to enable them to concentrate on the information and ask questions without feeling uncomfortable.

Men and women separate always. Women, they can't say, there's some things we can't talk, in our culture, we can't talk when the men are there, no.

SWI11, Sudanese woman

Age is also a factor. While older people and younger people can discuss sexual health issues amongst themselves, each may feel uncomfortable discussing such matter in the presence of the other generation. Older people can instruct younger people, but such discussion will not be free of the need to maintain certain traditional conventions of proper behaviour and standards.

On youth camps, they may have time to talk, and ask questions. It is better to talk to the kids by themselves. Some don't want to talk in front of their parents.

KII26, Somali man

Again, this highlights the need to tailor delivery of information to the intended audience, particularly where the topic is sensitive, embarrassing or contentious.

Moral context

The moral and framework of most African communities must be considered when developing materials. The influence of tradition and religion on the judgement of behaviour as good or bad, right or wrong, is strong. There is reluctance to endorse or support behaviour that is judged immoral by the traditional standards of the community.

If someone tell you that someone got HIV you can kill someone, you like just go and kill that person because in Sudan we believe it is bad, it is a shame, when you have HIV it means that you are a prostitute because you been moving with a man, that's how you get HIV, they don't know that HIV you can get even if you have a husband, one person can get it, you can get it through needles, you can get it through the sexual intercourse.

SWI11, Sudanese woman

In some cases there is a perception that allowing people to know of certain behaviour is tantamount to encouraging them to do it. However, there are many who are pragmatic about the need for people to know enough to protect themselves when engaging in behaviour that is disapproved of by the community, such as extramarital sex or drug use.

In the Islamic religion sex without marriage is forbidden. However the religion and the tradition not practised. If the people are not God conscious to use condom, the woman tell the partner not accept unprotected sex.

FGD6, Somali women

If you are already into drugs and using it, use it in safe way, discard the used needle, don't share needle usage.

FGD6, Somali women

It should be possible to engage community and religious leaders in the development of education strategies and materials that inform the community without contradicting the moral principles by which many of them try to live.

Conclusion

The findings reported here show that currently, the image of HIV/AIDS among the African communities of Victoria is similar to that in Africa. That is, it is a deadly disease, highly contagious, without effective treatment, and affects immoral people. Many members of African communities believe there is little or no HIV/AIDS in Australia, especially in their own communities. Where a risk is thought to exist in Australia, it is associated with homosexuality, drug use, loss of tradition, and particularly threatens the younger members of the community.

In Australia, it would seem that African immigrants are likely to be exposed to HIV infection through unprotected sex with partners that they view as “low risk”, such as spouses or regular partners, and others with similar backgrounds as themselves. Injecting drug use seems very uncommon, while traditional practices such as scarring are not performed in Australia.

Barriers to access to HIV/AIDS services in Victoria exist and are due largely to language difficulties, distrust of professional confidentiality, and fear of ostracism by the community. This affects both screening and treatment for HIV/AIDS.

During the project various strategies for reducing the risk of HIV/AIDS in African communities through education and improved services were considered. Firstly, awareness of HIV/AIDS as a local issue can be raised by informing the communities about the limitations of the pre-migration HIV test. Raising community awareness must be done without inducing fear and anxiety that may worsen the existing isolation of PLHA from their communities. Communities can be made aware of the existence of effective treatment for HIV that enables PLHA to lead happy, full lives, including the bearing and raising of children. They can also be made aware of how HIV is not transmitted, and informed of the safety of household and casual contact with PLHA.

The association with sexual immorality need to be addressed. On this issue, although sexual transmission must be mentioned, the possibility of medical or other blood borne infection exists for many people in Africa, and it is not often possible to determine the means of infection in an individual, compared to a population. This is a complex concept; however African immigrants have displayed understanding of other complex concepts related to HIV/AIDS, derived from previous public health information in Africa.

The third issue to be addressed is communication between African communities and health service providers, where language is an issue. Currently, interpreter services are insufficient to deliver prompt service when required in health care settings, and there is little confidence in the confidentiality of interpreters among African communities. Given the sensitive nature of HIV/AIDS, this presents a significant barrier to good communication between health care providers and community members. It will take a

large, long-term commitment to support the training, supervision and evaluation of interpreter services.

African communities themselves have stressed the need to be involved in the further assessment and response to the issues raised in this report. If members of African community organisations are involved, they will be able to identify key issues, ease communication between policy-makers and community, and provide feedback or evaluation of official responses and initiatives. Importantly, involvement of respected community members may allow discussion of sensitive issues, particularly where tradition is thought to be threatened.

Although the issue of HIV/AIDS in African communities in Victoria presents some difficult problems, these problems are not insoluble. If awareness of HIV/AIDS can be raised without arousing undue anxiety, if communities can become aware that effective treatment is available; if it becomes known that PLHA do not pose a threat to their family and friends and that the diagnosis of HIV does not indicate immoral behaviour; and if high-quality interpreter services are developed, there is scope for major improvements in health care of refugees, both HIV-related and in other areas.

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Appendices

Appendix 1: Information about HIV/AIDS virology

Appendix 2: HIV/AIDS and African migration

Appendix 1: HIV/AIDS virology

Human immunodeficiency virus

The human immunodeficiency virus (HIV) is a human retrovirus that infects multiple cell lines, notably the CD4+ T-lymphocyte, a white blood cell that is a key part of the adaptive immune system. It is a double-stranded RNA virus consisting of a core and an outer envelope. The genome of HIV consists of three genes: *gag*, *pol* and *env*, flanked by long terminal repeats containing other genes. There are two species: HIV-1 and HIV-2. HIV-1 is the species most commonly infecting humans, worldwide. HIV-2 is usually (but not exclusively) found in West and Central Africa.

The virus replicates in human cells by transcription of the mature viral RNA into DNA by the viral enzyme reverse transcriptase. The integrated genome then uses both viral and host cell-derived enzymes to produce mature virions that bud out from the host cell and go on to infect other cells (Mandell, Bennett et al. 2000).

Genetic diversity of HIV

HIV displays great genetic diversity due to its error-prone replication process and frequent recombination. In an infected individual, the single infecting strain rapidly and progressively diversifies into a host of related quasi-species. In an infected population, strains isolated from infected individuals can be classified into a “phylogenetic tree” made up of clusters of viral genetic sequences (usually *env*, *gag* or *pol* genes) that are related to each other to greater or lesser degrees.

On this basis, there are three main groups of HIV-1: M (main), O, and N. All have been isolated in Africa, from whence the global pandemic probably originated. Most strains circulating globally are of group M. group M is subdivided into subtypes A-H, and J-K, on the basis of genetic sequencing and phylogenetic analysis. A number of strains circulating within populations have arisen from recombination of different subtypes. These are known as circulating recombinant forms (CRF). Subtype E has only been isolated in recombinant form. The Los Alamos National Laboratory (LANL) HIV Sequence Database contains records of the genetic sequences, subtype, and details of origin of all published HIV genetic sequences, available online at (<http://hiv-web.lanl.gov>).

Pathogenesis of HIV-related disease

The pathogenesis of HIV-related disease is early, acute, massive CD4+ T-lymphocyte depletion several days after infection, followed by chronic immune system activation and dysregulation, marked by a steady decline in peripheral CD4+ T-lymphocyte numbers, and resulting in progressive immune deficiency (Derdeyn and Silvestri 2005). Clinically, a seroconversion illness occurs 1 to 6 weeks after infection. Manifestations include fever, generalised lymphadenopathy, rash, and a variety of other symptoms and signs. A clinical recovery usually occurs, and the infected individual remains relatively asymptomatic until severe immunodeficiency has occurred.

The acquired immunodeficiency syndrome (AIDS) occurs at a median of 9.8 years after infection in untreated individuals. AIDS is defined by the diagnosis (in a person with antibodies to HIV) of one or more conditions such as specific opportunistic infections (such as tuberculosis or PCP), or malignancies (e.g. cervical cancer, Kaposi’s sarcoma), or the decline of their peripheral CD4+ T-lymphocyte count to less than 200/mm³. In

untreated individuals, the median survival from diagnosis of AIDS is 12 to 18 months (Mandell, Bennett et al. 2000).

Transmission of HIV

Transmission of HIV occurs in only a limited number of ways: sexual mostly by contact between genital or rectal mucosa and infected genital secretions; parenteral (blood-borne) through contaminated blood transfusion, organ transplantation, multiple use of poorly-sterilised surgical instruments, or sharing of needles or paraphernalia associated with injecting drug use; finally, mother-to-child transmission can occur during pregnancy, delivery or breastfeeding (Mandell, Bennett et al. 2000; Hoy and Lewin 2003).

Preventing sexual transmission of HIV

HIV infection can be prevented by the adoption of various protective behavioural and organisational strategies. On an individual level, proven strategies are: abstinence from sex with people infected (or possibly infected) with HIV; and use of condoms during vaginal and anal sex.

At a population level, reduction of sexual transmission can be achieved through the promotion of: condom use; reduction in number of sexual partners; and delay of sexual activity until later in life. The relative effectiveness of each of these strategies is still debated (Pinkerton and Abramson 1997; Foss, Watts et al. 2004; Okware, Kinsman et al. 2005; Stammers 2005).

Preventing parenteral transmission of HIV

Prevention of parenteral transmission of HIV at an individual level can be achieved by avoidance of sharing needles and paraphernalia during injecting drug use (Gowing L 2004).

At a population level, the following measures are effective: interventions aimed at reducing IDU and needle-sharing; screening of donated blood and organs for HIV; adoption of universal precautions in health care settings (treating all blood and bodily fluids as potentially contagious); minimisation of surgical instrument re-use; and adequate sterilisation procedures (2005).

Preventing mother to child transmission of HIV

Prevention of mother to child transmission of HIV can be achieved by antenatal treatment of HIV-infected pregnant women with effective antiretroviral therapy, and avoidance of breastfeeding by HIV-infected mothers. Delivery by Caesarean section and avoidance of invasive foetal monitoring also reduce transmission, but it is not clear whether these provide additional benefit above that of antiretroviral treatment (Hoy and Lewin 2003). Most of these measures depend on the diagnosis of HIV in the woman before pregnancy, if possible - certainly before delivery.

Diagnosis of HIV infection

Diagnosis of established HIV infection is usually straightforward, by detection of several HIV-specific antibodies that generally appear within three months of infection. At an earlier stage of infection, this HIV antibody test may be negative or equivocal; in such cases, the diagnosis can be established by detection of HIV antigens such as p24, or by polymerase chain reaction (PCR) amplification and characterisation of HIV RNA or proviral DNA (Mandell, Bennett et al. 2000).

Treatment of HIV infection

HIV infection is not curable, but effective treatment can maintain health and prolong survival. Current drug therapies reduce viral replication (reverse transcriptase inhibitors and viral protease inhibitors), or interfere with viral attachment to host cells (fusion inhibitors). Novel therapies are being investigated. Vaccines (for prevention of infection or disease progression) are also being researched. The first effective antiretroviral treatment, single drug therapy with zidovudine, improved survival among HIV-infected people diagnosed with AIDS, but did not prevent progressive immune system damage. Since 1996, combination therapy with three or more antiretroviral drugs has reduced mortality and progression to AIDS for HIV-infected people (Palella, Delaney et al. 1998), as well as improved survival for people already diagnosed with AIDS (Wood, Hogg et al. 2003). This type of treatment is known as highly active antiretroviral therapy (HAART). HAART is very effective, but does have both short and long-term adverse reactions, and requires a high degree of adherence to complicated dosing regimens to maintain its effectiveness and prevent the emergence of resistant virus (Hoy and Lewin 2003). The cost and complexity of HAART delayed its availability to the developing world for many years; however this is changing, and large scale treatment programs are underway in many regions in Africa, and Asia.

Appendix 2: HIV/AIDS and African migration

There has been some clinical research into HIV in African immigrant populations in Europe, North America and Israel. A fairly consistent pattern is evident. Late diagnosis is common. From national surveillance data in Australia, 60% of African-born people diagnosed with HIV present late (i.e. three months or less between HIV diagnosis and AIDS diagnosis)(2005). An Australian study by Dore et al showed HIV diagnosis was late in 45.5% of African-born subjects, compared to 17.9% for those born in Australia (Dore, Li et al. 2001). In the UK, Del Amo found that African people with HIV were more likely to present with AIDS than non-Africans (OR 1.5, 95%CI 1.1 – 2.0) (DelAmo, Petruckevitch et al. 1998). Also in the UK, Boyd found that Black Africans with HIV presented with AIDS in 21.3% of cases, compared to 9.9% of White patients (P=0.02) and presented with a lower CD4 count (median 223/mm³ compared to 358/mm³ for White patients)(Boyd, Murad et al. 2005).

Tuberculosis is the commonest AIDS-defining illness for people born in Africa. In the cohort reported by Dore et al, the risk of TB as initial AIDS-defining illness among sub-Saharan Africans much higher than that for Australian-born people with AIDS (OR 18.69, 95%CI 9.15 – 38.19, P <0.0005) (Dore, Li et al. 2001). Del Amo in UK also found that TB was the initial AIDS-defining illness in 27% of African cases, compared with 5% of non-African cases (DelAmo, Petruckevitch et al. 1998).

The prognosis and response to adequately provided treatment of African immigrants with HIV is not different to that of HIV+ people from industrialised countries. Due to the late presentation of African patients with HIV, the prognosis of HIV-infected immigrants from Africa may appear poor, but when adjusted for age, stage at presentation, CD4 count at presentation and AIDS-defining illness, the mortality and rate of progression of Africans with HIV in Del Amo's UK cohort was no different to that of other patients (DelAmo, Petruckevitch et al. 1998).

The social context of HIV for African immigrants has been examined in some studies abroad. Fear of stigmatisation, reluctance to disclose the diagnosis, and concern for the impact on families are key issues (Erwin, Morgan et al. 2002; Anderson and Doyal 2004; Åsander, Belfrage et al. 2004; Doyal and Anderson 2005).

References

- (2004). Fact Sheet 22. The Health Requirement. DIMIA, Commonwealth of Australia: 3.
- (2004). Settlement Database, Australian Department of Immigration and Multicultural and Indigenous Affairs.
- (2004). Table 86. Population, sex country of birth, states and territories, 2001 census (usual residence). Australian Historical Population Statistics. Canberra, Australian Bureau of Statistics: 1.
- (2005). HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia annual surveillance report 2005. HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia annual surveillance report. A. McDonald. Sydney, National Centre in HIV Epidemiology and Clinical Research: 1-139.
- (2005). Infection Control Policy. D. o. H. AIDS and Infectious Diseases Branch, NSW Health: 1-56.
- Anderson, J. and L. Doyal (2004). "Women from Africa living with HIV in London: a descriptive study." AIDS Care 16(1): 95-105.
- Åsander, A.-S., E. Belfrage, et al. (2004). "HIV-infected African families living in Stockholm/Sweden: their social network, level of disclosure and knowledge about HIV." International Journal of Social Welfare 13: 77-88.
- Boyd, A. E., S. Murad, et al. (2005). "Ethnic differences in stage of presentation of adults newly diagnosed with HIV-1 infection in south London." HIV Medicine 6(2): 59-65.
- DelAmo, J., A. Petruckevitch, et al. (1998). "Disease progression and survival in HIV-1-infected Africans in London." AIDS 12(10): 1203-1209.
- Derdeyn, C. A. and G. Silvestri (2005). "Viral and host factors in the pathogenesis of HIV infection." Current Opinion in Immunology 17(4): 366.
- Dore, G. J., Y. M. Li, et al. (2001). "Spectrum of AIDS-defining illnesses in Australia, 1992 to 1998: Influence of country/region of birth." Journal Of Acquired Immune Deficiency Syndromes 26(3): 283-290.
- Doyal, L. and J. Anderson (2005). "'My fear is to fall in love again.' How HIV-positive African women survive in London." Social Science & Medicine 60(8): 1729-1738.
- Dutertre, S. and S. McNally (2006). Access to HIV prevention information among selected culturally and linguistically diverse (CALD) communities in Victoria. Monograph Series. Melbourne, Australian Centre for Research in Sex, Health and Society: 1-204.
- Erwin, J., M. Morgan, et al. (2002). "Pathways to HIV testing and care by black African and white patients in London." Sexually Transmitted Infections 78: 37-39.

- Foss, A. M. r. f. i. m. m., C. H. s. l. i. e. a. h. p. Watts, et al. (2004). "Condoms and prevention of HIV. [Editorial]." BMJ 329(7459): 185-186.
- Gowing L, F. M. B. R. A. R. (2004). "Substitution treatment of injecting opioid users for prevention of HIV infection." The Cochrane Database of Systematic Reviews: Reviews 2004 Issue 4 John Wiley & Sons, Ltd Chichester, UK DOI: 10.1002/14651858.CD004145.pub2(4).
- Hoy, J. and S. Lewin, Eds. (2003). HIV Management in Australasia: a guide for clinical care, Australasian Society for HIV Medicine.
- Mandell, G. L., J. E. Bennett, et al., Eds. (2000). Principles and Practice of Infectious Diseases, Churchill Livingstone.
- Okware, S., J. Kinsman, et al. (2005). "Revisiting the ABC strategy: HIV prevention in Uganda in the era of antiretroviral therapy." Postgraduate Medical Journal 81(960): 625-628.
- Palella, F. J., K. M. Delaney, et al. (1998). "Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection." New England Journal of Medicine 338(13): 853-860.
- Pinkerton, S. D. and P. R. Abramson (1997). "Effectiveness of condoms in preventing HIV transmission." Social Science & Medicine 44(9): 1303.
- Stammers, T. (2005). "As easy as ABC? Primary prevention of sexually transmitted infections." Postgrad Med J 81(955): 273-275.
- Wood, E., R. S. Hogg, et al. (2003). "Is there a baseline CD4 cell count that precludes a survival response to modern antiretroviral therapy?" AIDS 17(5): 711-20.