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Photo cover: Jacqueline Papo

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# Clinical Guidelines for antiretroviral therapy management for displaced populations - Southern Africa

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# I. Preamble

Providing HIV-related services to displaced populations is a difficult yet critical undertaking, which is firmly rooted in international human rights law. Protection offered under this law and, in particular, article 12 of the International Covenant on Economic, Social and Cultural Rights, confirms "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health". This right requires health workers to take steps that are necessary for "the creation of conditions which would assure to all medical service and medical attention in the event of sickness". I

In addition, health workers who treat displaced persons are guided by the same principles that govern the treatment of any patient before them, irrespective of nationality or ethnic origin, which include an intrinsic respect for human life and an oath to act in the patient's best interest when providing medical care.

Nonetheless, displaced persons are a unique group with special needs. They are often stigmatised, marginalised and discriminated against, making them highly vulnerable and insecure in their host country. Those in need of treatment are often denied care. However, since the rollout of affordable antiretroviral therapy (ART) worldwide, there has been an international push to recognise every individual's right to treatment and to ensure universal access to ART. Displaced persons often come from communities that are least likely to have access to ART, and health workers will be following international law and practice by providing treatment to them.

For those who are already on treatment, health workers often need guidance regarding complications that may arise due to differences in regimens or, if initiated in the host country, due to different conditions the individual may face at the site they will be going to. The management of ART in displaced populations requires health workers to make strategic choices regarding the best care for the individual who may be further displaced. These guidelines outline key principles to guide the health worker in making these sometimes complex choices.

# Scope of application

This policy is intended to offer guidance to clinicians, non-governmental organisations (NGOs) and governments on the provision of ART among displaced populations, including prevention of mother to child transmission (PMTCT), post-exposure prophylaxis (PEP) and long term ART. These guidelines are not meant to replace national guidelines but to provide additional guidance to health workers to deal with the specific needs of these populations.

As with all HIV and AIDS policies and programmes, ART must be linked to prevention, care and support programmes. ART should not be implemented as a parallel intervention but rather as part of an integrated programme that is in itself linked to other existing services (e.g. reproductive health, nutrition, education and social services).

The guidance set forth in this document applies to all displaced populations, including refugees, asylum seekers, internally displaced persons and migrants. Specific guidance is necessary not only due to the unique characteristics of these populations, but also due to their specific vulnerabilities and frequent exclusion from HIV and AIDS related services. It is widely recognised that the failure to provide HIV prevention and care to displaced persons not only under-

mines effective HIV prevention and care efforts, it also undermines effective HIV prevention and care for host country populations.

II. Background

Southern Africa is host to approximately 300,000 refugees and asylum seekers, the majority of whom are hosted in South Africa and Zambia. Most refugees and asylum seekers are currently coming from countries with lower HIV prevalence, such as the Democratic Republic of the Congo (DRC) and moving to countries with higher HIV prevalence, such as South Africa. Their vulnerability to HIV infection, therefore, increases upon arrival. In general, they also come from areas where access to ART is limited.

The number of migrants in the region is difficult to estimate accurately, as there are no official mechanisms for recording these figures. However, every country in southern Africa is

"They see refugees as a threat, as competing for their jobs and women. Nobody sees them as a victim of circumstances."

Refugee in Johannesburg referring to local services

affected by migration, either as a source or destination country.

#### **Definitions**

- **Refugee**: a person who flees his/her own country because of race, religion, nationality, membership of a particular social group, political opinion or civil unrest/war, and who cannot return home for fear of persecution
- Asylum seeker: a person who has applied for asylum and is awaiting a decision on his/her case
- Internally displaced person: person who has been forced to flee his/her home suddenly or unexpectedly due to armed conflict, internal strife, systematic violations of human rights or natural disasters, and who is still within the territory of his/her country
- Economic migrant: person who moves to another country seeking economic opportunities
- **Undocumented migrant** (often negatively referred to as 'illegal immigrant'): person who has entered another country and remains without the required legal documentation

# **Mythbusters**

#### 'Conflict always increases HIV'

On the contrary, despite the sexual violence, trauma and breakdown of family and community structures, evidence suggests that there are 'protective' factors in a refugee setting that may offset these risks. Furthermore, displaced persons often come from countries of origin with lower HIV prevalence and move to countries of asylum with higher HIV prevalence. II Thus, these populations often have lower HIV prevalence than their surrounding host communities, particularly in southern Africa.

# 'Displaced persons engage in high risk behaviour'

While displaced persons are vulnerable to exploitation and abuse, they have often benefited from the assistance of international organisations. For example, dedicated HIV awareness programmes and training in many refugee camps have resulted in a high level of skills and knowledge with less risky behaviour. Displaced people can use this knowledge in their country of asylum as well as upon return to their home country. IV

# 'High mobility among displaced persons prohibits good adherence'

Displaced persons are often denied access to care for fear that they are too mobile. However, by the end of 2003, refugee populations remained on average in their host country for 17 years. Even within a country, they are far less mobile than many assume and may move around less than local clients who work far from home.

# 'Providing care will bring on a flood across the border'

As HIV and AIDS related care is made increasingly available in the region and as more people can access such services, the more they tend to stay where they are. In countries that have provided free ART to refugees, there has not been an increase in movement across borders.

# 'Displaced persons never have support structures'

There are often tight and extensive support networks of similarly affected people within the host community; these may, however, not involve family, friends or more traditional support networks. Often innovative ways of ensuring adherence to ART, such as using clinical staff, counsellors and support groups, have proven effective.

#### 'Conflict is limited to a short period'

Unfortunately, most conflict lasts for years and decades, resulting in conditions that force displaced people to remain in their host countries for extended periods.

# III. Responsibility of the Health Worker

It is the role of health workers to act, within a legal framework, as advocates for access to health care, and not to restrict or ration care. The ethical duty of a health worker is to treat patients in a manner that serves the patient's best interest.

Medical assistance should ensure the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health" vi and must be offered without discrimination. People in need of health care should not be denied HIV care because of their nationality.

# IV. Medical Management

All people, including displaced persons, should be encouraged to regularly test for HIV.

Retesting for HIV should occur in all patients who report being HIV positive. This must be done with their informed consent. Counselling should be made available if results from re-testing are negative and confirmatory testing/expert consultation sought.

As is the case with the general population, people from displaced communities may present late with AIDS-defining illnesses, as well as for PEP and antenatal care. Advanced presentation is *not* a reason to deny care. Earlier diagnosis should be pursued at every opportunity.

Displaced persons may be anxious that disclosure of their HIV status will have implications for their residency, resettlement and other legal consequences. The reality is that HIV status does not have an impact on the legal status of a displaced person in the southern African region.

Despite this, displaced persons may be anxious about disclosing their HIV status. Some refugees may wish to remain anonymous for a myriad of reasons, including very real security concerns. It is up to the health worker to deliver care in a manner that does not put them or their families in danger. Health workers must reassure patients that their privacy and confidentiality in this regard will be respected.

A full history, clinical, psychosocial and available laboratory evaluation should be done for all patients according to the national protocol.

# 1. Antiretroviral Therapy (ART)

ART is a life saving intervention.

In principle, ART should be lifelong and thus sustainability should be key. However, even if sustainability is not guaranteed or is uncertain,

immune reconstitution on ART, even for short periods, can yield significant clinical benefits. Furthermore, provision of ART is rapidly evolving in

the region, and is increasingly accessible even in very poorly resourced areas. Hence, starting someone on ART for even a limited period of time may allow them to access more sustainable treatment at a later stage. However, there is substantial evidence that ART interruptions may be harmful, and this option must be carefully weighed and generally only considered in severe disease.

Adherence support needs of displaced persons may be very different from those of the local community. A displaced person may not have the traditional support of family or friends, although there may be strong cohesion among displaced communities who share similar reasons for displacement. As the circumstances of displaced persons often change without warning, assistance needs should be constantly assessed, and appropriate counselling and support provided where necessary.

# 1.1 Initiation criteria for patients with no ART history

## **Patient preparedness**

Patients must make an informed decision to begin and be adherent to ART and, as with other patients, proper counselling is key to ensuring the displaced person's understanding of these principles. Counselling in an appropriate language and with due regard for cultural differences is crucial. UNHCR has translation resources available for refugees.

Counselling should also take into consideration

the particular background and human rights context of the displaced person. The possibility of treatment interruptions should they be further

displaced must be specifically addressed during counselling, e.g. if they travel to a different area, they may need to find an alternative drug supply and HIV care network. The possibility of interruption should not be used by the health worker as a reason to deny access to care. Instead, strategies should be explored with the displaced person to find solutions.

In the event of informed refusal of ART, as with any other patient, continued counselling is required. Furthermore, access to other interventions including prophylaxis and treatment of opportunistic infections should not be withheld.

"From what I have seen, compliance ground and hu

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among foreigners is good, better than

South African citizens."

South African doctor

#### **Country-specific exclusion criteria for ART**

These criteria should be viewed very critically, taking into consideration the specific circumstances of displaced persons. Certain criteria may need to be modified to include displaced persons in ART programmes. For example, some programmes ask for a 'treatment buddy', which can be a challenge for displaced persons who are often alone or separated from traditional support structures. Imaginative solutions are usually available and should be explored (see *Solutions Box* below).

## **Biological criteria for initiation of ART**

National guidelines should be adhered to, where these are available. Where there are no national guidelines, World Health Organization (WHO) guidelines should be followed.

The absence of laboratory facilities should *not* be used to exclude HIV infected people from treatment. For example, if a displaced person does not have access or cannot afford CD4 testing at initiation, WHO guidelines clearly state that clinical staging is an acceptable indicator for ART initiation.

# If return to country of origin or further movement is imminent

The following considerations should govern the decision to immediately commence ART:

- i: ART is a lifesaving treatment and should be carefully evaluated in each case, regardless of whether return or further displacement is imminent.
- ii: In many cases, the conditions and access to ART at the site being travelled to is unknown. Information may be out of date in many cases, especially as ART access has expanded so rapidly. Conflict may interrupt access to previously accessible health services. Displaced persons may therefore

- return to HIV care systems that may be either stronger or weaker than they, or the assessing health worker, anticipated.
- iii: Stage of disease and anticipated availability of treatment at the site being travelled to should guide the urgency of initiation.
- iv: If patients have advanced clinical disease (severe AIDS-defining disease or a low CD4 count (<50 cells/ul), they should be advised to delay their departure and ART commenced immediately. However, clinical discretion is required in all cases.
- v: If the patient is WHO stage 3 or healthy, with a good CD4 count (if available) and
  - > treatment is available at the site being travelled to:
    - The site of initiation (either at the current health site, or at the site being travelled to) should be determined by the following factors: timing of departure, duration of travel, ART regimen at the receiving site (if known), anticipated side-effects and conditions on arrival (e.g. local waiting time to access ART). All these need to be discussed with the patient so an informed decision can be made.
  - > treatment is NOT available at the site being travelled to:
    - The displaced person should be encouraged to remain where they are and initiate ART for at least 3 months to monitor potential side-effects and adherence, and subsequently be provided with a stock of medication for 3-6 months if possible.
  - > individual insists on leaving immediately or in the near future:
    - These individuals must receive comprehensive advice on options available (see below). All should be considered suboptimal.

Options include:

- a) leaving with no ART
- b) initiation for a short period prior to leaving together with additional ART stock
- c) leaving with a supply to be initiated at the site being travelled to
   (with referral letters and extensive pre-adherence counselling)

The guidelines group felt that option (b) and (c) were dangerous, and should only be considered in exceptional circumstances.

In many situations, the person will be going to an area with poor or limited health care, limited or no access to clean water or accommodation and food insecurity. In this situation, option (a) may be more appropriate.

For other individuals who are going to better conditions and have a good understanding of HIV and ART, options (b) and (c) may be considered if this is the only option. Consequences of initiating ART in the (b) and (c) scenarios may include developing sideeffects in an unsupported environment, possible development of ART resistance due to the lack of adherence support, and the difficulties of initiating and maintaining treatment during a stressful and unstructured time. These consequences must be fully explained to the patient.

- vi: There may be additional reasons for delaying treatment initiation, other than those listed above, such as patient readiness, practical considerations (such as sideeffects during travel and reintegration), concurrent medical conditions that may worsen on ART (e.g. immune reconstitution diseases may present catastrophically and the receiving site may not have the resources to manage them), and other considerations. The risks and benefits of deferring treatment must be carefully weighed against immediate initiation; options should be discussed with the patient, including delaying departure.
- vii: This decision-making may require significant ART expertise, and the health worker should consult if not confident that s/he has the expertise to give adequate counsel.
- viii: Choice of regimen: In general, try to match the regimen to the one the individual is most likely to be on over the next year. If return or displacement is likely to be soon, try wherever possible to match the regimen to that available in the area the person is going to.

SOLUTIONS BOX		
Solutions to problems encountered when initiating patients on ART		

Problems	Solutions
CD4 count is unavailable or unaffordable	→ WHO clinical staging is simple, and relatively sensitive and specific
Treatment buddy is required by national guidelines	→ Use a friend, companion, family member, support group, ocal health worker, or local faith-based or non-governmental organisation (NGO) member
No counsellor is available who speaks the language	→ Contact UNHCR for list of translators
Payment, lab costs, transport costs are an obstacle	→ Displaced persons must be assisted with a waiver process if one exists; others can be referred to NGOs and social welfare organisations, which are also resources in many areas. Refugees can be referred to UNHCR.
Geographical exclusion criteria exist, but patient is unable to return to home site	→ If outside treatment catchment area, patient must demonstrate ability to regularly attend appointments and then assisted to negotiate for inclusion with the relevant authorities

# 1.2 Patient presents on ART or with history of previously taking ART

In circumstances where the displaced person is either currently on ART, or has a history of previously being on ART, the following is recommended:

- A repeat HIV test to confirm their infection.
- If the individual is currently on ART, continue treatment with no interruption.
- If possible, a viral load and CD4 count should be done at the time of the first visit. If the viral load is raised (according to the national protocol), adherence intensification is usually warranted. Expert opinion should be sought before ordering resistance testing, if available.
- If there has been a treatment interruption, try

to restart treatment as soon as possible, after careful assessment of the reasons for the interruption (see below). The viral load may be high if the interruption is significant.

 Adherence counselling and support should be undertaken in light of the new circumstances.

# **Choice of regimen if currently on ART**

In general, most patients in sub-Saharan Africa are currently initiated on d4T or AZT, 3TC and a non-nucleoside reverse transcriptase inhibitor (NNRTI), either nevirapine or efavirenz.

- ➤ If on same regimen as national programme:
  - Continue same regimen.
- ➤ If on different regimen from national programme:
  - If the national guideline supports the different regimen, continue with this regimen

and initiate monitoring according to the local algorithm. Occasionally, the national regimen protocols may offer better treatment options, or new treatment options may become available, and these cases should be assessed with suitable expertise.

- If the national guideline does not support the regimen, the following possibilities should be considered, as they may not allow patients to go on to the regimen indicated under the national protocol:
  - history of side-effects and co-morbidities
  - history of possible virological, immunological or clinical failure
  - use of concomitant medication

In this case, select the best available regimen from available drugs.

- ➤ If on unknown regimen, with minimal history
  - In general, these patients should be initiated on the national guideline's first line therapy, and followed closely. Where possible, a viral load after 6 weeks of treatment should be used to indicate efficacy and a significant drop in viral load (1-log) should be anticipated if the regimen remains effective.

#### **Choice of regimen if ART was interrupted**

Establish the cause of the interruption. Note that displaced persons are at greater likelihood of treatment interruption due to factors beyond their control, e.g. conflict resulting in displacement from their normal ART site.

"They saved my life."

Migrant in Johannesburg on ART through faith-based organisation

#### **Routine evaluation:**

- ➤ If adherence is an issue, this needs to be explored. However, there is no evidence that displaced persons are less adherent than local populations.
- ➤ If virological failure was the reason, treat as per national protocols, which may mean accessing second line regimens, if available.
- ➤ If due to side-effects, subsequent drug choices should be carefully evaluated.
- ➤ If interruption was due to drug supply issues, and there were no adherence, resistance or toxicity issues, ART should be reinitiated as soon as possible.
- ➤ If the previous regimen was the same as the national programme, restart ART. Nevirapine deserves special consideration in the event of the patient having a high CD4 count, as it is associated with significantly increased toxicity. If nevirapine is restarted after an interruption of >1 week, recommence with the 2 week lead-in dose, and monitor alanine transaminase closely for the first 3 months of treatment, if laboratory monitoring is available.

If the previous regimen is different from the current recommended regimen, considerations should be as above.

## 1.3 Contingency planning

Displaced persons can be affected by unforeseen events, causing them to move unexpectedly. This needs to be explored at every visit.

Discuss the provision of a personal ART stock where assessed to be necessary (2-4 weeks will allow for time to make alternative plans for ART access).

All patients should have a clinical HIV summary, such as a treatment card, which includes their

drug regimens, prior toxicity, illness history and laboratory results. All patients should also be aware of their basic medical history and be able to relate it verbally. This assists continuity of treatment in the event of unplanned displacement.

If on an NNRTI regimen (which have a long half-life) and treatment is stopped with no possibility of immediate restocking of drugs, consider "covering the tail" (the long half-life of NNRTIs) by continuing dual nucleosides for a week after stopping the NNRTI, to prevent possible NNRTI resistance.

In the event of unplanned displacement, patients should be cautioned on non-reputable sources of treatment, including counterfeit drugs, cheaper but less effective regimens (such as dual therapy), inconsistent sources of drugs, and poorly trained health worker advice. They should be counselled to seek continued care only through a public or reputable programme.

Sharing of ART and dose reduction/interruption to extend the stock lifespan must be discouraged.

#### 1.4 ART-specific challenges

The choice of ART should take the following into account:

- National guidelines should be used. Within this, try to match this regimen to the possible regimen in the area being travelled to, if travel is anticipated soon.
- Some ARVs (e.g. ritonovir) require refrigeration. Assess availability of refrigeration during travel and at the site they are travelling to and adapt ART accordingly.
- Some ARVs require food intake for optimal absorption. Many regimens require twice daily dosaging. Displaced persons may not have sufficient food available and should be told to take their medications despite lack of food, and warned of possible increased gastrointestinal side-effects. At the same time, food aid should be sought for these persons.
- In many cases, patients may be on fixed-dose combinations (FDCs) in their prior ART site, and this may mean a higher pill burden in

# Mythbusters

# 'Resistance to ARVs is caused by suddenly stopping ART'

Stopping ART suddenly is rarely associated with resistance; poor dosing, poor drug quality and poor adherence are far more common causes. There is concern about stopping NNRTIs along with other classes of drugs, as they have a long half-life. This is discussed above.

# 'Access to monitoring is poor and hence ART should not be started'

If laboratory monitoring is not available, clinical monitoring, although sub-optimal, is sufficient to start ART.

# 'Access to guaranteed lifelong therapy is a reason not to start ART'

Treatment may allow a person to live long enough to access more sustainable sources of ART, especially as broader availability increases throughout the region. However, there are dangers in interrupting treatment, and this must be avoided wherever possible.

their new site if the FDC is not available. The changes should be carefully explained during adherence counselling.

- If the ART choice requires more frequent monitoring, consider the ease and cost of access to the displaced person. As with local populations, transport costs are often a barrier to regular visits.
- ARVs requiring reconstitution (some paediatric formulations) depend on access to clean

water, which may not be easily available to displaced persons.

 The absence of access to laboratory monitoring (either due to lack

of facilities or cost) in the current site or site being travelled to should not be used to exclude people from ART. Minimum standards for laboratory monitoring are outlined in the WHO and national guidelines, and should be adapted as much as possible to enable access. If the ART choice requires more frequent monitoring, consider ease and cost of access. For example, a nevirapine regimen should ideally have liver function monitoring in the initiation phase, which may increase the frequency and cost of visits. However, in many cases, nevirapine is the only NNRTI available, and no liver function testing is available, in which case the drug should be initiated with extensive patient counselling.

# 1.5 Management of children

Initiation of treatment should be based on national guidelines. In certain cases, if diagnostic and monitoring facilities are not available, refer to the WHO guidelines for HIV diagnosis that are based on a positive HIV antibody test and clinical findings.

Syrup formulations have large volumes, and can be difficult to carry and refrigerate. This may be particularly relevant to those travelling long distances and should be taken into consideration when making clinical decisions.

In children <18 months who are diagnosed clinically, parents should be counselled to seek confirmatory testing after 18 months of age

with conventional antibody tests. This is particularly important where further displacement is possible.

save my mealiemeal for my funeral."

Namibian refugee in Botswana, on ART

through a faith-based organisation

"People are surprised to see me looking

so well. Before they were advising me to

Unaccompanied minors

are a special issue, and may need to follow a special legal process or agreed upon guardian/caregiver arrangements. These need to be expedited as quickly as possible, so as not to delay ART. For refugee children, contact UNHCR for assistance.

#### 1.6 Post-exposure prophylaxis (PEP)

In populations affected by conflict, gender-based violence and assault is common throughout the cycle of displacement. Sexual exploitation is also common among female migrants, who can be victims of trafficking. PEP should be considered for displaced persons in need; however, assessment often takes place after the efficacy of PEP has passed. PEP includes HIV, sexually transmitted disease and pregnancy prevention. Trauma and adherence counselling is essential in all cases.

National and WHO/UNHCR<sup>vii</sup> PEP guidelines should be followed. If national guidelines

exclude displaced persons, treatment should be accessed wherever possible (e.g. from rape crisis centres, NGOs, faith-based organisations, private practitioners). For refugees who cannot access PEP through a local service, contact UNHCR urgently.

# 1.7 Prevention of mother to child transmission (PMTCT)

PMTCT services may not be available in the prior site; and hence women may not have been counselled regarding PMTCT. Pregnant women may require counselling on testing, treatment and feeding options available in the host health care environment.

In cases of moving to sites with unknown or poor access to care, similar to treatment for tuberculosis in pregnancy, the pregnant woman and her family should be advised to delay moving until after delivery in order to complete the PMTCT programme.

In cases of moving to sites with established PMTCT programmes, the patient should be advised to immediately seek out local PMTCT programmes on arrival. However, due consideration to the stage of pregnancy, duration/mode of travel and conditions on arrival must be discussed.

A clear referral letter is important at all times, in both the antenatal and postnatal period.

Provision of PMTCT drugs to pregnant women about to move should be considered in case labour occurs during travel or the woman arrives in an area where there is no PMTCT programme. Take note of the considerations described in the section that deals with individuals in need of ART who are facing imminent departure (see section 1.1 Initiation Criteria

for patients with no ART history > If return to country of origin or further movement is imminent) to counsel appropriately.

## 2. Non-ART considerations

# 2.1 Tuberculosis (TB) treatment, and primary and secondary prophylaxis for opportunistic infections including cotrimoxazole, fluconazole and isoniazid

National guidelines should be followed. Interruption of prophylaxis should be avoided through rapid referral to local sites providing these drugs. People with TB should be encouraged to complete TB treatment before further movement.

Cotrimoxazole demonstrates significant benefit in areas affected by malaria and bacterial infections, as well as in people with WHO stage 2,3 and 4 disease. Cotrimoxazole should be strongly considered, in line with national and WHO guidelines.

A contingency stock of prophylactic medications, as for ART, is recommended for people at risk of unplanned movement (2-4 weeks supply, like ART).

#### 2.2 Other illnesses

Malaria is extremely common in the region, but typhoid, trypanosomiasis, viral hepatitis, cholera, amoebiasis, measles and other diseases that can affect travellers should be considered, and appropriate prevention advice given.

Be aware of other countries' endemic AIDS defining diseases that may not be common in

the host country (e.g. kala-azar in Somalia, histoplasmosis in Zimbabwe).

# 2.3 Language

Using family members or community members as interpreters carries risks regarding respect for confidentiality and inappropriate disclosure, and should be avoided where possible. Furthermore, information may be less forth-coming through a third party if the party is known to the person. All efforts should be made to have an independent interpreter who has been trained in issues of confidentiality.

Ongoing adherence counselling is a challenge if no ready interpreter is readily available.

For refugees, do not refer them to their country's embassy, as that may jeopardise their asylum status. This may be an option, though, for other displaced persons, e.g. economic migrants.

For help with refugees, contact UNHCR, who may be able to identify suitable interpreters.

#### 2.4 Referral letter

Note that due to language issues, the health worker at the distant site may not speak or read the referring site's language, and may not be able to read the referral letter or treatment card of the referring site. Use generic names and terms such as stavudine, tuberculosis, cryptococcal meningitis and internationally agreed upon abbreviations or acronyms such as PMTCT or VCT (voluntary counselling and testing). Referral letters may get lost. Therefore, explain the contents of the letter to the patient, so they can relay information verbally if necessary.

## 3. Other important issues

#### 3.1 Cultural issues

The background and culture of a displaced person may be different to that of the host country. Health workers should be culturally sensitive and non-judgemental. Regardless of cultural traditions or practices, the health worker should maintain professional standards and practices, although this may require additional time and effort. For example, if a man insists on knowing the HIV test results of his spouse without her consent, as this is his 'right' according to his culture, a more detailed explanation of the principles of confidentiality and disclosure may be required.

#### 3.2 Alternative treatments

As with many local communities, displaced persons may seek alternative treatments. Encourage them to share this information with the health worker, so that informed treatment decisions can be made. In almost all cases, drug interactions between ART and alternative medication are unknown, and should be discouraged where possible.

# 3.3 Psychosocial and mental health<sup>Viii</sup>

Displaced persons, particularly those coming from conflict areas, may have experienced trauma and violence, including sexual violence, and therefore may be in need of specific psychosocial support. These issues should be explored sensitively and efforts to refer to specialised services should be made.

History taking may provoke anxiety, depression and stress responses. Appropriate counselling should be made available.

#### 3.4 Prevention

Southern Africa is an area of very high HIV prevalence. In some cases, displaced persons will be moving into a high HIV risk or higher prevalence environment (e.g. from Somalia to South Africa). Displaced persons should be made aware of increased HIV risk. Some populations have very limited knowledge of prevention methods, such as condoms, and health workers must not assume core knowledge exists.

For those already living with HIV, prevention messages must be re-emphasised to avoid further infections.

Prevention messages, verbal or written, must be communicated where possible in the displaced person's language.

The essential linkage between prevention and treatment is as relevant in this situation as with the host general population.

# 3.5 Reproductive health<sup>iX</sup>

Family planning availability needs to be carefully explained. Issues such as access to contraception, termination of pregnancy, emergency contraception and availability of ante/postnatal care should be outlined for all displaced persons.

Specific care options may not be known to the person due to unavailability in area of origin (e.g. contraceptive methods, pap smears); these new options should be explained.

## 3.6 Gender-based exploitation and violence $^{\times}$

Sexual violence often accompanies conflict and consequent displacement.

Displaced persons are often economically vulnerable, and may be at increased risk of sexual exploitation and abuse. In particular, women and girls may be more susceptible to HIV due to gender discrimination and violence, insufficient access to HIV prevention information and services, inability to negotiate safer sex and lack of female-controlled HIV prevention methods.

Information anticipating this, especially regarding PEP and psychosocial support, should be provided.

A careful and sensitive history should be taken in all cases. In cases of prior sexual assault, appropriate systematic care, support and treatment should be initiated, as per national guidelines.

# 3.7 Orphans, separated and vulnerable children

The nature of displacement often results in family separation. There may be an increase in orphans due to conflict and a related increase in communicable diseases. Displaced children may also be accompanied by a relative or another adult who is not a relative. If there are any concerns regarding the guardianship or care arrangements for the child, refer directly to social services for assessment.

Specialised counselling may be required for these children.

Red Cross/Red Crescent and other organisations facilitate tracing of family members and return of children to their country of origin.

Consent issues are covered in the paediatric treatment section (see section 1.5 Management of children).

#### 3.8 End-of-life care

Treatment options closer to the person's home may need to be explored in the event of limited mobility. Palliative care options vary, and support is often available in the host country through government programmes and NGOs. Refugees wishing to return to their country of origin should contact UNHCR.

## 3.9 Death and body disposal

Body transport across borders may be expensive, logistically complex and bureaucratic. International organisations rarely facilitate the transport of a body to the home country, although faith-based organisations may.

In the case of terminal patients, this information should be sensitively explained to the patient and their family members, and any available support offered.

## 4. Advocacy

Health workers should advocate for non-discriminatory medical practices, and must play an active role in reducing discriminatory attitudes and dispelling myths regarding displaced persons.<sup>X</sup>

Concerning refugees and asylum seekers, many countries in southern Africa, such as Namibia, South Africa and Zambia, have specific policies that include these groups in their public sector ART programmes. Others, such as Mozambique, Malawi and Zimbabwe do not specifically exclude refugees or asylum seekers from public sector ART. As at March 2007, Botswana is the only country with a policy that specifically excludes non-nationals from the ART programme. However, UNHCR and other organisations are advocating the government to lift this restriction.

Where policy restrictions exist precluding ART access in the public sector, migrants, refugees and others should be referred to NGO, faithbased or private sector ART programmes.

#### 5. Case studies

## Case One: THEMBI

Thembi is a Botswana national who has a work permit for South Africa (SA) and is working there as a cashier. She has just arrived in South Africa, after spending a year on the Botswana national programme. She has lost her referral letter and only plans to return to Botswana in six months. She says she is on tenofovir, 3TC and nevirapine, dosed daily, and is considering having a child with her South African husband. She previously was on d4T, but developed a peripheral neuropathy and was switched to tenofovir. She has sufficient medication for an additional week.

She is refused access to the ART site in the government programme in SA, as it is not available to economic migrants. She goes to a private practitioner, but does not have money to pay for a viral load or CD4 count. The practitioner is unable to obtain the records from the Botswana site. Clinically, she is well. She claims complete adherence and says that her previous viral load, taken 6 months ago, was 'OK'.

The practitioner advises her that tenofovir is not yet readily available in SA. d4T is not an option, due to her previous peripheral neuropathy, nor is ddl, both substitutes for tenofovir. AZT and abacavir are options as substitutes, although abacavir remains very expensive, and AZT ideally requires haematological monitoring, with attendant costs.

Introducing a single new drug to replace tenofovir in the face of a virologically failing regimen carries the risk of resistance to that drug, if no viral load is obtained to confirm suppression. The practitioner persuades Thembi to pay for a single viral load, funded through her local church. The result comes back undetectable. He substitutes tenofovir with AZT, carefully explaining the new twice daily dosing she now requires. She asks why other patients are on efavirenz, and why she isn't. The practitioner explains that established nevirapine is very safe, and that a switch is not advised, especially if she plans to have a baby, due to concerns regarding the teratogenicity of efavirenz. He asks her to try to obtain her past medical records as soon as possible. Thembi is advised to return if she experiences any side-effects, and is asked to see if the church has further resources to pay for haemoglobin and further viral load monitoring.

#### Case Two: MACHOZI

Machozi is a 28 year-old married woman from Eastern DRC. Like most of the women in her area, she has never been to school. Four years ago, she was working in her fields when a group of soldiers moved through the area. Seeing her in the field, they took her hostage and forced her to carry their goods. They then forced her to 'marry' one of the commanders.

Over the next 4 months she was repeatedly raped. Finally she was able to escape her captors, and in fear of being re-captured, she fled over the border of Zambia. She settled in a small town and made a meagre living selling items in the market. Then over several months, she started to lose weight. She noticed as well that her skin had broken out in a rash that

wouldn't go away. At first she thought she had been poisoned by one of the market women but finally the nurse at the health centre convinced her to have an HIV test. The test was positive and she was referred to the HIV clinic.

The doctor who saw Machozi at the clinic evaluated her as clinically WHO stage 3. He prescribed cotrimoxazole and ordered a CD4 count. The CD4 came back as 124, and the doctor decided to start preparing Machozi to start ART. However when he discussed this with Machozi, she didn't seem to understand. In fact, she told the doctor that she had decided to return home, and therefore could not come back to the clinic. The doctor explained how important it was to stay in Zambia and start ART. Machozi nodded, but still insisted that she must go home. She told the doctor she would take the pills home with her if they were so important.

The doctor considered this option. Machozi was newly diagnosed and while she seemed to understand her diagnosis, the doctor could not be sure, given the language difference and the short time he had known her. A pill count of her cotrimoxazole showed that she had some pills left over. He asked Machozi to describe the health care in her home village. Machozi described the small basic health centre with a single nurse in the town one hour's walk away. She described how much it cost to see the nurse and how often there were no drugs in the health centre. Considering Machozi's current state of preparedness for ART, the uncertainty that lay ahead when returning home, and the poor level of the local health care system, the doctor decided not to start Machozi on ART before leaving. Instead, he advised her to try and seek out an NGO HIV programme when she returned home. He gave her a 3 month stock of cotrimoxazole tablets and reviewed again with her how to take the pills correctly. Finally he wrote a letter describing her medical history and explained to her the contents of the letter.

# Displaced Persons and HIV care: Challenges and Solutions

Laurie Bruns, MS Paul Spiegel, MD MPH United Nations High Commissioner for Refugees

Countries in southern Africa host a variety of displaced populations: refugees and asylum seekers who have fled conflict or persecution in their country; internally displaced persons who are still within their country; and economic migrants moving in search of employment. Regardless of the reason for displacement, all persons have the right to the 'highest attainable standard of health' 1, including HIV-related care. However, the displaced person's ability to access care can be fraught with challenges. They often do not speak the language in the area to which they have moved. They might not be familiar with local systems or services. They may have knowledge gaps, particularly related to HIV and AIDS, and have specific support needs due to the lack of traditional community and family support structures. But one of the greatest barriers to access to care is one that can be easily surmounted: reluctance on the part of health professionals, from to nurses to clinicians, to make the extra effort necessary to deliver services to such individuals.

The reasons for this reluctance are varied. Certain myths about displaced persons persist, such as the belief that they are more likely to engage in high risk behaviour, or that they are too mobile to adhere to antiretroviral therapy (ART) and therefore would pose a risk of developing resistance. None of the available evidence supports these perceptions; on the contrary the evidence we have for refugee populations, for example, demonstrates fewer risky behaviours in comparison with the host community<sup>2,3</sup>. However, every situation is context specific and must be evaluated as such.

By the end of 2003, refugee populations remained in their host country for an average of 17 years<sup>5</sup>. Furthermore, behavioural surveillance surveys show a high level of interaction between refugee and host communities; clearly the exclusion of displaced persons from local HIV and AIDS-related services is detrimental to efforts in HIV prevention, care and treatment to both displaced persons and the surrounding host communities<sup>4</sup>.

According to the World Health Organization (WHO), the largest threat for developing resistance to ART is persons taking their medications in an incorrect manner<sup>6</sup>; this threat is no larger for displaced populations than for other populations.

Differing treatment regimens and treatment interruption from area of origin to the area of displacement may also pose a challenge to clinicians. However, clear guidance on this issue has been developed through a consultative process led by the Southern African Clinicians Society and UNHCR (included in the journal).

Lack of awareness of the rights of displaced persons, together with xenophobia, can lead health professionals to deny care. In a survey conducted among urban refugees in South Africa in 2003<sup>7</sup>, 30% of respondents who had been denied emergency medical care, which is guaranteed to everyone under the national Constitution, reported that the denial came directly from a doctor or a nurse. The reasons given varied, but many practitioners showed a lack of familiarity with refugee rights, as well as a belief that such services were 'only provided to South Africans.'

In fact, the HIV care needs of displaced persons are, for the most part, not different to those of local patients; a bit of empathy and creativity will go a long way towards finding ways of providing the same quality of services to these populations. In a number of countries in the southern African region, creative approaches to some of these challenges have already been employed. In Botswana and South Africa, local non-governmental organisations (NGOs) maintain a roster of trained interpreters to help with communication and adherence support. In Mozambique and Namibia, UNHCR and its NGO partners provide support for transport from refugee camps to the nearest ART site. UNHCR has also produced or translated existing HIV information materials into local refugee and migrant languages. These materials are a very effective means of educating patients whether dealing with prevention, care or treatment. The only problem was language, which again, with a bit of initiative, has been quite easily overcome.

WHO, together with UNHCR, UNICEF and other international organisations, recently held an expert consultation on delivering antiretrovirals in emergencies. In the consensus statement from this meeting, they conclude:

'That emergencies...should not affect one's access to HIV services and that the provision of such services is not only feasible, but an inalienable human right and a public health necessity.<sup>8</sup>'

HIV knows no borders,

Addressing the HIV- related needs of displaced persons in an equitable, non-discriminatory manner is a critical intervention in the fight against HIV and AIDS, particularly in sub-Saharan Africa.

#### **References:**

- International Convenant on Economic,
   Social and Cultural Rights (ICESCR)
- 2 UNHCR. HIV and AIDS Behavioural Surveillance Survey, Marratane Refugee Camp, Mozambique. November 2005.
- 3 Spiegel, PB. HIV/AIDS among conflict-affected and displaced populations: dispelling myths and taking action. *Disasters*. 2004;28(3):322-339.
- 4 UNHCR. Antiretroviral Medication Policy for Refugees. Geneva, January 2007.

- 5 UNAIDS, UNHCR: Strategies to Support the HIV-related needs of refugees and host populations. Geneva: UNAIDS Best Practice Collection, 2005.
- 6 WHO. HIV drug resistance; http://www.who.int/hiv/drugresistance/en/. Geneva, 2006.
- 7 Japan International Cooperation Agency (JICA) & UNHCR. National Refugee Baseline Survey: Final Report. November 2003.
- 8 WHO, UNAIDS, UNHCR, UNICEF, Medecins sans Frontieres, et al. Consensus statement: Delivering Antiretroviral Drugs in Emergencies: Neglected but Feasible. 2006.

# 6. Key documents

United Nations High Commissioner for Refugees. Note on HIV/AIDS and the Protection of Refugees, IDPs and Other Persons of Concern. Geneva: UNHCR, 2006

Joint United Nations Programme on HIV/AIDS, United Nations High Commissioner for Refugees. Strategies to support the HIV-related needs of refugees and host populations. Geneva: UNAIDS Best Practice Collection, 2005

Inter-Agency Standing Committee (IASC). Guidelines for HIV/AIDS interventions in emergency settings. Geneva: IASC reference group, 2004

United Nations High Commissioner for Refugees. Antiretroviral Medication Policy for Refugees. UNHCR, 2007. <a href="http://www.unhcr.org/hiv-aids">http://www.unhcr.org/hiv-aids</a>

United Nations High Commissioner for Refugees. Sexual and Gender-based Violence against Refugees, Returnees and Internally Displaced Persons: Guidelines for Prevention and Response. UNHCR, 2003

United Nations High Commissioner for Refugees. Protracted Refugee Situations, Standing Committee 30th meeting. EC/54/SC/CRP.14. Geneva: UNCHR, 10 June 2004

World Health Organisation. Antiretroviral Therapy for HIV Infection in Adults and Adolescents: Recommendations for a public health approach. WHO, 2006 <a href="http://www.who.int/hiv/pub/guide-lines/artadultguidelines.pdf">http://www.who.int/hiv/pub/guide-lines/artadultguidelines.pdf</a>

Antiretroviral therapy of HIV infection in infants and children in resource-limited settings: towards universal access. WHO, 2006. <a href="http://www.who.int/hiv/pub/guidelines/WHOpaediatric.pdf">http://www.who.int/hiv/pub/guidelines/WHOpaediatric.pdf</a>

Southern African HIV Clinicians Society guidelines: Adult and paediatric ART, and pre-ART guidelines. <a href="http://www.sahivclinicianssociety.org/">http://www.sahivclinicianssociety.org/</a>

Spiegel PB. HIV/AIDS among Conflict-affected and Displaced Populations: Dispelling Myths and Taking Action. *Disasters* 2004;28(3):322-39

Wong KH, Chan KC, Lee SS. Delayed progression to death and to AIDS in a Hong Kong cohort of patients with advanced HIV type 1 disease during the era of highly active antiretroviral therapy. *Clin Infect Dis.* 2004 Sep 15;39(6):853-60

Badri M, Lawn SD, Wood R. Short-Term Risk of AIDS or Death in People Infected with HIV-1 Before Antiretroviral Therapy in South Africa: A Longitudinal Study. *Lancet*. 2006 Oct 7;368(9543):1254-9

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#### 8. Notes

- i International Covenant on Economic, Social and Cultural Rights, art 12, para 2 (d)
- Spiegel PB. HIV/AIDS among Conflict-affected and Displaced Populations: Dispelling Myths and Taking Action. *Disasters* 2004;28(3):322-39
- iii UNHCR/US Centers for Disease Control and Prevention/Zambian Ministry of Health. Zambia Antenatal Clinical Sentinel Surveillance Report, Kala and Mwange Refugee Camps, 2005
- UNHCR. Behavioural Surveillance Survey among Refugees and Surrounding Host Communities, Kakuma, Kenya, 2004; UNHCR. HIV and AIDS Behavioural Surveillance Survey, Marratane Refugee Camp, Mozambique. 2005; UNHCR/ Great Lakes Initiative on HIV/AIDS. Behavioural Surveillance Survey, Uganda. 2006
- United Nations High Commissioner for Refugees. Protracted Refugee Situations, Standing Committee 30<sup>th</sup> meeting. EC/54/SC/CRP.14. Geneva, 10 June 2004
- vi International Covenant on Economic, Social and Cultural Rights (ICESCR), art 12, para 1
- vii WHO/UNHCR. Clinical Management of Rape Survivors: Developing protocols for use with refugees and internally displaced persons. Revised Edition, 2005; UNHCR's antiretroviral medication policy for refugees, 2007
- viii Inter-Agency Standing Committee (IASC). IASC Guidelines on Mental Health and Psychosocial Support in Emergency Settings. Geneva: IASC, 2007
- ix UNHCR/WHO/UNFPA. Reproductive Health in Refugee Situations: an Interagency Field Manual. 1999
- Inter-Agency Standing Committee (IASC). Guidelines for Gender-Based Violence Interventions in Humanitarian Settings. Geneva: IASC Taskforce on Gender in Humanitarian Assistance, 2005; UNHCR. Sexual and Gender-based Violence against Refugees, Returnees and Internally Displaced Persons: Guidelines for Prevention and Response. 2003



