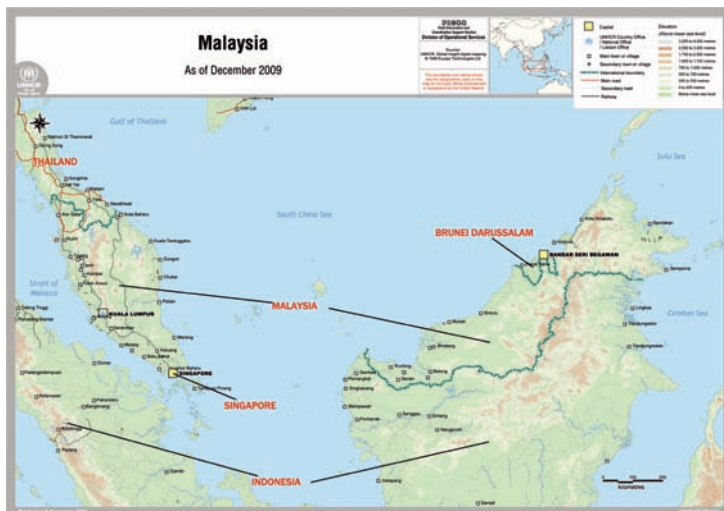


Support to Antiretroviral Therapy Adherence amongst Urban Refugees in Kuala Lumpur, Malaysia

Context

UNHCR Malaysia is currently providing protection and assistance to over 70,000 registered refugees and other persons of concern (PoCs), the majority of whom are composed of different groups from Myanmar. Other PoCs are from Sri Lankan (mostly Tamil) and several other nationalities including Iraqi and Afghan. Eighteen percent (18%) of the total population are women and 25% are children.



The refugees are mainly scattered throughout Kuala Lumpur/Kliang Valley with smaller numbers elsewhere in the country. Those that have been recognised by UNHCR have been issued with an official document that affords them some protection. Registered refugees accessing Government health services pay the same rate as nationals. UNHCR supports financial assistance for health care for vulnerable PoCs only.

Refugees are recognised under the HIV National Strategic Plan 2006-2010 as one of the marginalised and vulnerable populations. This plan incorporates

a multi-sectoral strategy covering issues from young people's vulnerability to the delivery of healthcare services and antiretroviral therapy (ART). Refugees with HIV/AIDS are able to benefit from free ART provided by the Government and UNHCR supports those costs that are not covered.

HIV Situation in Refugees in Malaysia

There has been a progressive increase in the number of reported HIV infections among refugees since 2003. However, this does not necessarily reflect an increase in HIV prevalence as this is likely due to increased access to information-education-communication interventions and HIV voluntary counseling and testing programmes that have been key component of UNHCR's HIV strategy. Of the 397 cases diagnosed since 2003, 70% were among males and over 95% from Myanmar. There are 268 active cases of whom 124 (46%) persons are receiving ART supported by both the Ministry of Health in Malaysia and UNHCR. All are receiving treatment at the Sungai Buloh Hospital, the Infectious Diseases Hospital in Kuala Lumpur.

Actions for Change

All of the potential challenges in taking life-long medications on a daily basis may be greater in displaced populations and are particularly challenging for urban refugees. There were concerns regarding adherence to ART amongst refugees in Kuala Lumpur. Potential barriers to adherence for refugees in this setting included - language; difficulties affording and/or lack of knowledge regarding transport; poor nutrition and lack of food; fear of arrest and harassment when moving to access services; fear of accessing services due to stigma and discrimination; and living in close proximity with others from the same community resulting in reluctance to be seen taking large numbers of tablets. Stigma and discrimination relating to HIV remain a problem in the refugee communities, especially amongst the Rohingya of Myanmar; much of this is related to lack of knowledge but there are also cultural factors. Many of the refugees are from countries where there have been little or no HIV awareness activities, and it will take some time for their level of knowledge to improve, and even longer for attitudinal changes.

An HIV-positive refugee was met at the Welcome Home as he had defaulted and become unwell. The reason he gave for defaulting was that he had not been sure which number bus he had to catch to the hospital, and therefore, did not make it back for follow up. This underscores the need not only for detailed counselling on why and how to maintain adherence, but also social issues to ensure that refugees have all the information that they need to return for follow-up appointments.

The consequences of poor adherence can be severe. For the individual it can mean treatment failure, drug resistance, the need to take more complex therapy if available, more toxicity, and a more uncertain prognosis. From a public health perspective it can mean transmission of a resistant virus to others.

The only objective measure of adherence available among refugees in Kuala Lumpur was viral load suppression which was reported to be lower among refugees than nationals (approximately 30% and 70%, respectively, according to Sungai Buloh Hospital). The hospital reported that HIV-positive refugees had more extrapulmonary TB, more opportunistic infections, greater lengths-of-stay in hospital, and were more likely to get immune

reconstitution inflammatory syndrome as they were presenting with lower CD4 counts before starting on ART.



Malaysia / Hypertension due to stress is common among refugees. This refugee man is being checked by a volunteer doctor as his daughter looks on, at a mobile clinic in Kuala Lumpur. / UNHCR / S. Hoibak / April 2006

Interventions and Positive Outcomes

Sungai Buloh Hospital, UNHCR and its implementing partner, Malaysia Care, have taken a number of steps to support refugees on ART and facilitate adherence. The success of any adherence strategy depends on:

- the education of patients before the initiation of ART
- an assessment of their understanding of the therapy and their readiness for treatment
- assessment of potential barriers to adherence and how these can be overcome

Malaysia Care provides supportive counselling in an appropriate language (through interpreters) to refugees who are HIV positive, both before and after beginning ART. This counselling includes a discussion of factors that might affect adherence, and development of strategies to address these issues. Visual materials can be particularly useful in this process, and a counseling guide has been developed in a flipchart format.

Ongoing attention to and reinforcement of adherence throughout the entire course of ART comprises an essential part of any successful treatment, and has been built into the interventions. To this end, community level support is crucial; 16 community counsellors and 9 home-based care/awareness workers from the refugee communities, some of whom are nurses, have been trained to provide further counselling in the community and to be focal points for further information about ART and HIV services. Every person living with HIV/AIDS (PLHA) is assigned to a counsellor; counsellors have mobile phones and these numbers are given to the PLHAs to call in case of an emergency, thus functioning as a “hotline”.

Creating ‘enablers’ at the facility level has also benefited refugees. Sungai Buloh hospital has facilitated access by having a special day for refugees every Thursday. This facilitates follow-up as translators in refugee languages are made available on that day. Linkages have also been created between the facility and the community. Colored stickers are placed on the files of each patient so that the medical providers know which counsellor is in charge. If any problems arise, they will contact the counsellor in charge. Refugees collect their ART medicines from one pharmacy; if they fail to collect the drugs, their nominated counsellor is notified and follow-up occurs. Refugees who do not receive financial assistance are given transport cards to facilitate access to the hospital.

Reminders or tools to help refugees remember to take their medicines are important. Refugees are issued with dosage boxes which they prepare once a week and a dosage card to record whether or not medicines have been taken. Refugees are also encouraged to use mobile phone alarms if feasible. In addition, a treatment group that meets regularly to provide support for those on ART has been started in three locations around the city. These groups act as platforms to re-emphasise the importance of adherence and also to discuss their problems in accessing care.

Some ART require food intake for optimal absorption. Many refugees may be food insecure. UNHCR provides an allowance for PLHA who are on ART to ensure that they are able to maintain a satisfactory and nutritional food intake.

Although a formal assessment of ART adherence is being undertaken among refugees in Kuala Lumpur, following the introduction of these measures, the medical providers reported that viral load suppression in refugees had significantly improved and was comparable to nationals on ART. As a result of these steps taken by Sungai Buloh hospital, UNHCR and their implementing partners, barriers to ART adherence amongst urban refugees in Kuala Lumpur are being addressed, and refugees have been provided with essential tools for increasing adherence.

Conclusion

Refugees face challenges in both accessing and adhering to ART but these can be overcome with appropriate interventions. The possibility of treatment interruption should not be used as a reason to deny access to care. Instead, strategies should be explored with the displaced persons to develop mechanisms, both pre-treatment and during treatment, at the community and facility level to assist in maintaining ART adherence.

