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Prevention of mother-to-child transmission of HIV in a refugee camp setting in Tanzania

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Abstract
The objective of this article is to describe the results of a 2-year pilot programme implementing prevention of mother to child HIV transmission (PMTCT) in a refugee camp setting. Interventions used were: community sensitization, trainings of healthcare workers, voluntary counselling and HIV testing (VCT), infant feeding, counselling, and administration of Nevirapine. Main outcome measures include: HIV testing acceptance rates, percentage of women receiving post test counselling, Nevirapine uptake, and HIV prevalence among pregnant women and their infants. Ninety-two percent of women (n = 9,346) attending antenatal clinics accepted VCT. All women who were tested for HIV received their results and posttest counselling. The HIV prevalence rate among the population was 3.2%. The overall Nevirapine uptake in the camp was 97%. Over a third of women were repatriated before receiving Nevirapine. Only 14% of male counterparts accepted VCT. Due to repatriation, parent’s refusal, and deaths, HIV results were available for only 15% of infants born to HIV-infected mothers. The PMTCT programme was successfully integrated into existing antenatal care services and was acceptable to the majority of pregnant women. The major challenges encountered during the implementation of this programme were repatriation of refugees before administration of Nevirapine, which made it difficult to measure the impact of the PMTCT programme.

Keywords: Refugees, mother to child, HIV transmission
Introduction

Since 1994, it has been shown that mother to child transmission of HIV is largely preventable (Connor et al. 1994, Mary 2000). Administration of Nevirapine during intrapartum and neonatal periods has been shown effective and appropriate in developing countries (Guay et al. 1999, Marseille et al. 2000, Stringer, J.S. et al. 2003).

The United Nations High Commissioner for Refugees’ (UNHCR) 2002–2004 strategic plans (UNHCR 2002) clearly states that the prevention and mitigation of HIV/AIDS must be seen as an essential component of the overall protection of refugees. Data on HIV prevalence in refugee situations is scarce. However, refugees and other displaced populations are believed to be at increased risk of contracting the virus during and after displacement due to factors such as poverty, disruption of family, separation from social structures, increase in sexual violence, and interaction with the local communities and military presence (Santos-Ferreira et al. 1990, Zwi and Cabral 1991, Smallman-Raynor and Cliff 1991, Stringer, E.M. et al. 2003).

Although refugees are at increased vulnerability to HIV transmission, evidence from population-based surveillance has shown low prevalence rates in Sierra Leone (0.9%), Southern Sudan (2.3% among pregnant women), and Angola. All of these countries endured periods of protracted conflict with parts of their population isolated and inaccessible, with severely limited mobility (Kaiser et al. 2002, 2003, Spiegel and De Jong 2003, Spiegel 2004). Refugees’ settings present unique challenges for implementation of prevention of mother to child transmission (PMTCT) of HIV. The challenges include lack of an adequate number of counsellors and limited resources and infrastructure (Spiegel 2002a). Furthermore, lack of stability and high mobility, which is characteristic of the refugee populations, have been shown to affect the impact of other programmes, such as tuberculosis treatment (Kessler et al. 1998) and, therefore, are likely to impact the PMTCT programme as well. No previous studies have documented the implementation of PMTCT in a refugee setting. We present the results of the first 2-year pilot programme of implementing PMTCT in a refugee camp, for the period October 2002 through September 2004.

Context

Greater Lukole camp is located in Ngara district in Kagera region in western Tanzania, and is comprised of two adjacent camps known as Lukole A and B. Opened in 1993 for Burundian refugees, the camp was later expanded to accommodate refugees relocated from other camps and further influxes. During the implementation period, the camp population was approximately 90,000 refugees. UNHCR is responsible for coordination of refugee care and maintenance, which it does through both direct implementation (e.g., protection of refugees) and through working in partnership with Non Governmental Organizations (NGOs). One of these NGOs is Norwegian Peoples Aid (NPA), which is
responsible for direct implementation of health, community services, and education activities for refugees. Health services in the camp are provided through two in-patient hospitals, four outpatient clinics, including antenatal clinics (ANC), and community health workers. Table 1 provides a summary of selected health indicators of Lukole camp.

Tanzanian refugee camps have been implementing HIV/AIDS prevention and care activities since 1997. UNHCR and its partner NGOs, in collaboration with the African Medical Research Foundation (AMREF) trained HIV/AIDS counsellors and Tanzanian camps, were the first in Africa to implement voluntary counselling and testing (VCT) (Bakari et al. 2000). The United Nations Children’s Fund (UNICEF) carried out a baseline assessment in November–December 2000 and recommended that the PMTCT programme be implemented in the refugee camps and in districts around the camps. By early 2002 the UNICEF/UNHCR-supported PMTCT programme became operational and Lukole refugee camp was chosen to serve as a pilot site for the PMTCT programme in western Tanzanian refugee camps. At the time of implementation of this programme, there were five PMTCT pilot sites in non-refugee settings. Four sites were in national referral hospitals and the fifth was at Kagera regional hospital.

**Programme description**

The PMTCT programme in Lukole camp has the following components: (1) routine voluntary counselling and testing of HIV for all pregnant women; (2) infant feeding counselling for HIV-infected women; (3) oral administration of Nevirapine to HIV-infected women during labour; (4) oral administration of Nevirapine within 72-hours of birth of infants born to HIV-infected women; (5) modified obstetric practices and strengthening of universal precautions;
(6) follow-up for HIV-infected women and medical care of mother–infant pair; (7) referral to family planning, supplementary feeding, and home based-care; and (8) community participation and male involvement.

Preparatory phase

The preliminary phase (first 6 months) included the following activities: construction of facilities, mobilization of supplies (laboratory reagents, medical supplies), development of obstetric protocol, community wide sensitization campaigns, and health care workers trainings. The sensitization campaigns targeted volunteers working under the home-based care programme for people living with AIDS, traditional healers, religious leaders, school teachers, representatives of women’s groups, refugee camp leaders, and folk media groups.

Using the national PMTCT guidelines, consultants from the Tanzanian Ministry of Health trained health care providers on the basics of mother-to-child transmission of HIV, antiretroviral treatment, counselling, infant feeding counselling, modified obstetric care, and HIV testing with rapid kits. In addition, they were trained on reporting, recording, coding, and confidentiality issues.

Counselling

Voluntary counselling and testing (VCT) for HIV is now widely accepted as an effective HIV prevention and control strategy among heterosexual couples, particularly in sub-Saharan Africa (Smith 2002). In Lukole, all pregnant women attending antenatal services received routine health education at the waiting area. In addition, general issues related to HIV/AIDS and mother to child transmission of HIV were addressed. Registration began with assigning each pregnant woman a code so that the entire process is confidential.

In settings with high patient volume, extensive individual pretest and posttest counselling is not practical due to time constraints (Curt et al. 2005). The use of group pretest counselling, rather than one-on-one counselling, is a strategy that has been both successful and acceptable (Leyenaar 2004). In our programme, group counselling was conducted for 30–45 minutes for groups of four to six refugees. During group counselling the following topics were discussed: HIV situation in the camp; mother to child transmission during pregnancy, delivery, and breastfeeding, infant feeding options; and the concept of shared confidentiality. Shared confidentiality was used in this context to explain to the women that, once they were tested, their HIV positive status would be known to health care workers other than their counsellor (e.g., midwives, nurses in the maternity wards, doctors at the clinic, nurses at therapeutic feeding centres, etc.) during the delivery and follow up. Clients were informed of all available referral services, such as family planning and home-based care. Women were also encouraged to bring their partners and to ask questions.

The group counselling was followed by individual counselling, which was conducted in a private room for about 10–15 minutes. The purpose of individual
sessions was to establish whether women and their partners consented to the HIV testing and the use of Nevirapine. Those who agreed to be tested had to sign or thumbprint a consent form before testing. Women were informed that they had the right to decline testing (‘opt-out’), if so desired, at any point in the process. Counselling was conducted in the refugees’ native language (Kirundi). Two types of HIV rapid tests were used for HIV testing, Capillus HIV-1/HIV-2 (Cambridge Bio-technology, Galway, Ireland) and Determine HIV-1/2 (Abbott Laboratories, Abbott Park Illinois, USA). Different test kits were used if test results from Capillus and Determine methods did not match. If results remained discordant, the specimen was analysed by an ELISA test, outside the camp hospital. Test results were usually received on the same day except when an ELISA test was required. This would take approximately 3 weeks.

The same counsellor who did the counselling and testing explained HIV test results to each woman during the individual posttest counselling session. On average, each posttest session lasted 10 minutes for uninfected women and 15–20 minutes for HIV-infected women. HIV negative women were counselled on prevention of HIV infection, and encouraged to take another test due to the possibility of being in the window period. HIV-infected women received further counselling on the means available for reducing the risk of infecting their unborn babies and their partners. HIV-infected women continued to receive supportive counselling in subsequent visits. Women who refused to be tested continued to receive counselling during their subsequent clinic visits. Each of the four MCH clinics had four counsellors, making a total of 16 counsellors. Each counsellor attended to an average of 15 clients per day. After the first months, however, only new attendants needed testing and, therefore, the workload became less for the counsellors; they also became more competent and confident in their jobs. Counsellors took over the rapid HIV testing that was initially performed by laboratory technicians.

**Infant feeding**

The risk of vertical transmission through breastfeeding is well recognized, but safe alternatives are limited by socio-economic and environmental conditions in refugee settings (Seal et al. 2001). The current recommendations on infant feeding in a complex emergency situation emphasize the need to continue breastfeeding, unless feeding alternatives are acceptable, feasible, affordable, sustainable, and safe (WHO 2000, Bassett 2002). In Lukole camp, all HIV positive women received information regarding different infant feeding options. Even though formula feeding was discussed as an option, replacement products were not routinely provided; emphasis was placed on exclusive breastfeeding for 4 months followed by weaning. Under exceptional circumstances, physicians could give an ‘infant formula prescription’, where a counsellor was assigned to follow the women at home to assist them in milk formula preparation in case they had any difficulties.
Nevirapine

Counsellors provided every consenting HIV-infected woman with a 200 mg tablet of Nevirapine at 34 weeks of gestation. The tablets were to be taken at the start of labour. All HIV-infected women were encouraged to deliver at the hospital. A special code (known only to health care workers) helped to flag HIV-infected women presenting in labour. HIV-infected women were asked whether they had already ingested Nevirapine tablets. Women reporting to have taken the tablet more than 48 hours prior to admission, or vomiting within 30 minutes after ingestion, were given another dose of Nevirapine. Infants born to HIV-infected mother were given Nevirapine syrup (2 mg/kg single dose) within 8 hours after delivery. Similarly Nevirapine syrup was given within 72 hours of home deliveries. All these activities were duly recorded in the delivery and antenatal clinic registers.

Labour/delivery

Healthcare workers in the labour wards were trained on the components of the modified obstetric care protocol. The protocol included actions to be avoided during labour, such as artificial rupture of membranes (amniotomy), traumatic delivery, routine episiotomies, and suctioning of the newborn babies. Also included in the protocol were actions to reduce transmission of HIV, e.g. vaginal cleansing with chlorhexidine, immediate cleansing of newborn from maternal secretions, and using two separate delivery trays (for the mother and baby). Vaginal cleansing with chlorhexidine doesn’t reduce the MTCT rate overall but may be beneficial in a sub-group of women with prolonged duration of ruptured membranes (Biggar et al. 1996, Gaillard et al. 2001, Newell 2003). Vaginal cleansing with chlorhexidine has also been shown to be beneficial for preventing maternal and neonatal infections in a number of studies (Ahmad and Tarek, 2005), but the need for more well designed, randomized controlled trials, to estimate the effect of vaginal disinfection on MTCT and other infections, has been recommended (Lumbiganon et al. 2004, Wiysonge et al. 2005, Mullany et al. 2006).

Follow up of HIV positive women

Well known challenges of the VCT process include: not all women agree to be tested, not all those who are tested return for their results, and not all those who are HIV-infected will take antiretroviral drugs or give birth in the health facilities (Leonard et al. 2001). In anticipation of these challenges, the PMTCT programme in Lukole designed a follow up strategy that guaranteed confidentiality, and could also be used for monitoring and evaluation purposes. After the disclosure of results and posttest counselling, counsellors visited all HIV-infected women for supportive counselling.
Referral to other services

All HIV-infected women had access to information, referral care, and nutrition support through the supplementary feeding programme. Infected mother–infant pairs were referred to family planning and doctors’ clinics in the camp for routine medical care. In addition, HIV-infected women were automatically enrolled in the camp’s home-based care programme for people living with AIDS. Infants born to infected mothers were to be tested at 15 and 18 months using ELISA testing available at the district hospital.

Community participation and male involvement

Community education to promote VCT, which also involves men, is one of the approaches to bringing about behaviour change and reducing stigma (Spiegel 2002b). In Lukole camp, the community-wide sensitization process promoted and encouraged men to attend counselling and testing with their spouses. Men were reached in the streets and other facilities such as outpatients’ clinics. To provide a male friendly environment, counselling rooms were annexed away from routine antenatal activities. This room arrangement ensured privacy and had spacious seating arrangements that allowed couples to be together.

Collaboration with other programmes

UNHCR emphasizes the need for all HIV/AIDS interventions for refugees to incorporate the host government’s guidelines (Temmerman et al. 2003, Spiegel and Nankoe 2004). UNICEF/UNHCR/NPA established contact with the national PMTCT steering committee at the Ministry of Health. The initial trainings in the camp by the Ministry of Health consultants were the result of this collaboration. NPA participated in a national PMTCT technical meeting at the end of November 2002. Reporting forms from the Ministry of Health were adopted to suit the camp setting. At the regional level, NPA shared the PMTCT work plan and visited other programme sites to familiarize and learn from the Ministry of Health experience. Tanzanian women living in the villages around the camp, and who had access to antenatal care services, also received PMTCT services.

Methods

The PMTCT programme monitoring records included data from four antenatal clinics and two hospital’s delivery registers. Data from these registries were routinely entered and stored in the computer using EpInfo 2000 software. To enhance completeness and data quality of registries, staff were trained on data management. UNHCR consultants conducted additional training on monitoring and evaluation. Each antenatal clinic had three persons responsible for data entry and management. Quality control of records and data was also done through weekly review of registries and feedback from senior personnel. Pilot programme
data collection was conducted between October 2002 and September 2004. Sources of data were registries from the four antenatal clinics and two hospitals in Lukole camp. The registries had data on refugee and Tanzanian pregnant women. However, this study focuses on only refugee women. Descriptive analysis involved computing percentages of programme uptake indicators.

Results

The PMTCT programme in Lukole camps adopted the Tanzania’s Ministry of Health PMTCT guidelines and the Ministry of Health expert trained staff. All four MCH clinics in the camp (which also have family planning and STI treatment clinics) and the two hospital maternities provided prevention and care services as recommended in the minimum package (UNAIDS 2004). The programme achieved high training coverage for various health care workers in the camp. More than 80% of targeted health care workers were trained in the minimum package. Similarly, nearly 90% of targeted community groups were reached during sensitization campaigns.

Voluntary counselling testing acceptance rates

From October 2002 through June 2004, 10,666 pregnant women attended their first antenatal care services in the study sites. Of these, 10,129 (95%) received pretest counselling for HIV. The median age of the women was 22 years (range: 19–32) and the median gestational age was 22 weeks (range: 20–34). Of the 10,129 women who received counselling, 9,346 (92.3%) agreed to undergo HIV testing. This is inclusive of all women tested who chose to be tested during the first ANC visit, as well as those who tested in the subsequent visits.

HIV prevalence and Nevirapine uptake

The overall HIV prevalence among pregnant women who agreed to be tested was 3.2% (301/9346). All women who were tested received their results on the same day. Of the 301 HIV-infected women, 280 (93%) agreed to take Nevirapine at 34 weeks of gestation and three women refused. The reasons the three women refused to take Nevirapine included misconceptions on the role of Nevirapine. There was a belief that it was a new ‘family planning pill’ designed to sterilize HIV-infected women and their new babies.

A total of 109 (36.2%) of the women who tested positive for HIV were repatriated to Burundi and Rwanda before delivery. Of the remaining 189 HIV-infected women who delivered in the camp, 152 (80.4%) had hospital deliveries and swallowed Nevirapine at the start of labour under a nurse’s observation; 33 (17.5%) had home deliveries and reported swallowing Nevirapine; and four women did not swallow Nevirapine. Overall, when excluding women who were repatriated, Nevirapine uptake was 185/189 (98%) in the camp and 185/301 (61.5%) when including women who were repatriated. All newborn infants
received Nevirapine syrup within 72 hours. These results are summarized in Figure 1.

A total of 184 infants, born to HIV-infected mothers and eligible for HIV testing at 18 months old, were followed up. Only 27 out of the 184 infants (15%) were present at the camp for testing, the rest were ‘lost’ during the follow up period due to repatriation, deaths, and parents refusal for testing. HIV prevalence among those infants who were tested was 7.5%. Although indicative, this was not a representative sample of the infants born to HIV-infected women in the

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**Figure 1.** Schematic presentation of women accepting counselling and HIV testing process and receiving ARV prophylaxis in Lukole camp.
programme nor the paediatric population in the camp. None of the infants who tested positive for HIV had any clinical findings consistent with HIV. Figure 2 summarizes the outcomes of infants born to HIV-infected mothers.

A total of 1,457 men were counselled with their spouses, and 1,454 accepted HIV testing, representing 14.4% (1457/10,129) male involvement. The HIV rate among tested couples (34/1454) was 2.3%. There were 11 discordant couples.

Breast feeding/infant feeding

Of the 184 HIV-infected women, 180 (98.2%) opted for exclusive breastfeeding with early cessation (98.2%). The remaining four (2%) opted for replacement feeding and were provided with formula milk from the programme. All women were followed by PMTCT counsellors, and 86.7% of those on exclusive breastfeeding were able to maintain exclusivity for 4 months. Toward the end of 4 months, the women had to return to the therapeutic feeding centre (TFC) to be trained on proper preparation of weaning food provided at the MCH clinic.

Discussion

To the best of our knowledge, this is the first study to report on the implementation of PMTCT in a refugee setting. Results of the first years of prevention of mother to child HIV transmission in Ngara refugee camps demonstrate successful implementation with high uptake of major programme components. Despite unique challenges in a refugee setting, data from this programme compare very well with other Nevirapine-based PMTCT programmes in non-refugee settings in Africa (Msellati et al. 2001, Etiebe et al. 2004, Urban and Chersich 2004). Strengthening of health systems has been identified as an important prerequisite in the prevention of HIV infections (Buve et al. 2003). In some settings, there are situations when refugee camps may have better health care systems than surrounding non-refugee districts. For example, in
a post-emergency phase, refugee camps tend to have better preventive and curative health services (Spiegel 2004). Such was the case for Ngara camps, which have been in existence for more than a decade. The existing health services and infrastructure in Lukole camp (e.g., high antenatal coverage, qualified medical staff, and stable health conditions with low mortality, morbidity, and malnutrition rates, and good health information system) may have contributed to successful implementation of the PMTCT programme. Likewise, the existing community-based HIV/AIDS prevention and care activities, such as home-based care, voluntary counselling and testing, youth reproductive health, and Sexually Transmitted Infections (STI) treatment, had already contributed to a high level of awareness of HIV/AIDS in the camp. The PMTCT programme, therefore, was seen more as an additional package in comprehensive HIV/AIDS prevention and care. Probably other major contributing factors in the success of the programme were intensive trainings of health care workers in all aspects of PMTCT. In addition, having a sufficient number of counsellors placed at antenatal clinics may have contributed to the success of the programme. Proximity to health facilities, and the relatively small camp area where pregnant women could easily be traced, played a role as well.

Advances in technology have greatly reduced turnaround times for test results. Rapid HIV testing results in higher uptake of VCT in many settings, because the gap between testing and getting the results is a matter of hours (Center for Disease Control and Prevention 1998, Downing et al. 1998, Kasler et al. 1998, Malonza et al. 2003). Just like in other settings, the availability of rapid testing with results given the same day of an antenatal visit may have contributed to the high uptake of HIV testing in the refugee camps. A small proportion of HIV infected women (17%) delivered at home, despite being encouraged to deliver at the hospital so that additional precautionary measures could be taken to further reduce the chances of HIV transmission during labour. Although all of these women reported that they swallowed Nevirapine as instructed, we had no way of confirming whether or not they actually took the drugs. However, all of these women immediately brought their newborns to the hospital for Nevirapine syrup. Only four women chose replacement feeding/breast milk substitutes over breast-feeding. This study did not examine reasons for the low acceptance rates for breast milk substitutes, but we suspect three reasons may be contributory. First, fuel wood needed to boil water for preparing infant milk formula is very scarce in Lukole camp and refugee women walk many miles to collect it. Second, even if resources were to be made available, the other dilemma is the repatriation-taking place, and people having to consider what kind of support they would have upon return to their country of origin. Third, fears of stigma for those using formula, not breastfeeding, would perhaps label them.

It is important to point out that the implementation of the PMTCT pilot programme took place during a period of heightened voluntary repatriation of Burundian refugees. This was a big challenge in the PMTCT implementation. Of the 109 HIV-infected refugee women who were repatriated, 83.5% (91/109) were
repatriated after collecting Nevirapine at 34 weeks (which was recommended in the national PMTCT guidelines). Many reported at the clinics that they were leaving, but others left without information. We do not know if these women established any contact with the PMTCT programme in their country. There was no information on the availability of PMTCT services in Burundi or Rwanda for refugee women who were returning home. Similarly, it is hard to measure the impact of this programme on the reduction of MTCT; nearly 89.2% (140/157) of infants born to HIV-infected mothers were lost to follow-up due to repatriation, and their outcome could not be determined (see Figure 2). This programme did not explore the feasibility of administering Nevirapine at the time of the first positive test or self-administration of Nevirapine, which has been tried in other African programmes (Temmerman et al. 2003, Kagaayi et al. 2005), and which would have been an alternative approach suitable for this type of setting with high mobility.

Couple counselling has been shown to be more effective in increasing uptake for HIV prevention (Farquhar et al. 2004). In a different study, one of the factors that influenced pregnant women to accept VCT in North Western Tanzania was the participation and commitment of their partners throughout the process (De Paoli et al. 2004). In both studies, pregnant women felt comfortable when men were involved; the process of results disclosure and sharing the diagnosis was much easier and resulted in a higher uptake of Nevirapine and formula feeding. In Lukole, the PMTCT programme elicited male support from the beginning. It was observed that there was a gradual but steady increase in the number of males attending counselling and testing sessions with their spouses. We believe the recorded 14.4% of male involvement is highly encouraging for a programme that had to overcome fear of discrimination and stigma among the refugee community at the beginning. Overall, HIV seroprevalence of 3.2% among refugees in Tanzania appears to be within a similar range as those reported from other refugee camps in East Africa (Uganda 5.2%, Southern Sudan 2.3%, and Kenya 0.6–5%; Spiegel 2004).

**Lessons learned**

Several lessons have been learned in the Lukole programme that may be useful in other refugee settings:

1. **Policy, coordination, and supervision.** The PMTCT programme for refugees was not included in the Tanzania Ministry of Health National HIV/AIDS Strategic Plans. However, the programme benefited from the technical assistance provided by the Ministry of Health experts, who introduced and trained camp staff on the Tanzania PMTCT guidelines. UNHCR and UNICEF worked with the MoH, and NPA was later invited to participate in the National PMTCT Steering Committee meetings, where progress was presented and spurred interest, and further collaboration with MoH was established. Lack of cross border cooperation, between the PMTCT
programme in the camps and those in the refugees’ countries of origin (Rwanda and Burundi), continues to be a challenge. Immediate cross-border programming needs will have to be addressed urgently. Field-level co-ordination, between UNHCR, UNICEF, NPA and refugee groups, was very good.

2. Monitoring and evaluation. The development of the monitoring and evaluation systems was challenging, and recording forms were complicated and time consuming. It took several trainings for staff and support supervision to have the system in place. It is hard to measure the impact of this programme in terms of reduction of MTCT of HIV due to repatriation of large numbers of infants born to HIV-infected mothers.

3. Quality of services. Several areas have implications on the quality of services. The programme recruited additional staff and trained all health care workers on various aspects of PMTCT. Periodic repeated training of staff was necessary because of high staff turnover due to repatriation. Counselling, which is central to the PMTCT programme, was supported by the availability of rapid testing with same day results. The workload for the health staff decreased after the first few months of the programme start. The proportion of HIV-infected women delivering at home, although small (17%), poses a unique challenge because precautionary measures are best provided at the hospital with trained staff.

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