REFLECTIONS

Reflections on a decade of delivering PMTCT in Khayelitsha, South Africa

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Implementation of a flagship PMTCT programme in Khayelitsha

Great progress has been made in the prevention of mother-to-child transmission (PMTCT) of HIV in the past ten years in South Africa, and this is reflected in the achievements of the health services in Khayelitsha. Located 56 km from the centre of Cape Town, Khayelitsha has an estimated population of 500 000, with a 38% unemployment rate. Forty-five per cent of the population live in formal housing. Antenatal (ANC) HIV seroprevalence increased from 19.3% in 2000 to 37% in 2011 and is the highest in the Western Cape.[1]

The Provincial Government of the Western Cape (PGWC) started the first PMTCT programme in South Africa in Khayelitsha as a primary-healthcare-level demonstration project on 4 January 1999, despite opposition by the National Ministry of Health. The School of Public Health and Family Medicine at the University of Cape Town was tasked with the monitoring of this pilot, and in September 1999, Médecins Sans Frontières (MSF) added technical support. Voluntary counselling and testing (VCT) was provided at one midwife obstetric unit (MOU) and short-course zidovudine (AZT) was dispensed by midwives from 36 weeks of gestation and during labour. Later the pilot was extended to a second MOU, and in 1999, 74% of pregnant women agreed to testing and 16% were found to be HIV-infected.[2]

Initially, antiretrovirals were provided only to prevent transmission to the child. Maternal AZT was stopped after delivery and no further HIV services were available for treating the mother. Continuity of care was poor as ANC and postnatal child health services were fragmented and provided by different health authorities. A clinician at the time recalled, 'On learning they were HIV-positive, women would commonly ask, "When am I going to die?" All we had to offer was treatment to reduce the risk of the baby being infected, but no treatment to keep the mother alive, to see her child grow up.'

After complex negotiations in February 2000, MSF opened the first service for pregnant, HIV-infected women requiring antiretroviral therapy (ART) in Site B. MSF extended the HIV services and ART to everyone who was eligible, according to World Health Organization (WHO) guidelines, and to two further sites in Khayelitsha. However, legal and regulatory barriers to generic antiretroviral imports delayed service implementation and drug supplies until 2001. Postnatal women from the PMTCT programme initially constituted the majority of ART referrals.[3] Nine postnatal clinics provided free formula milk for those who elected to perform replacement feeding.[2,4]

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Despite scientific evidence on the effectiveness of PMTCT, the AIDS-denialist views of President Thabo Mbeki and Health Minister Manto Tshabalala-Msimang led to a significant delay in the development of the national PMTCT programme, resulting in thousands of infant infections and subsequent deaths. In a landmark court case brought against the government by the Treatment Action Campaign (TAC), nevirapine (NVP) was made available nationally by order of the Constitutional Court in 2002 and a national PMTCT programme was implemented. NVP was the regimen established in two 'pilot sites' per province. The implementation of the national programme was slow, with wide geographical variation. By this time, the Khayelitsha PMTCT sites were well established, and VCT coverage was over 95%.[3]

Implementation of more efficacious PMTCT regimens

The Western Cape was also the first to launch a province-wide PMTCT programme by 2002/2003. Faced with a difficult choice

between national policy at that time (single-dose NVP) and the more complex regimens, such as AZT from 28 weeks of gestation with the addition of single-dose NVP, a technical meeting was held with policy makers, researchers and clinicians, including representation from the Perinatal HIV Research Unit (PHRU) and the French National Agency for AIDS Research (ANRS). It was decided that both interventions were equally effective. The MSF-supported Khayelitsha sites moved to the more complex regimen in 2003, consisting of AZT from 28 weeks of gestation and single-dose NVP given to all HIV-positive mothers in labour and to infants post delivery. The effectiveness of this programme at a primary care level was demonstrated in Khayelitsha in 2004, when PMTCT coverage was reported to be 77% and mother-to-child transmission 8.8%.[5]

While the national PMTCT programme continued to supply single-dose NVP for pregnant women, the Western Cape provided both AZT and NVP in 2004 and enhanced the PMTCT programme by expanding it throughout the province as a nurse-driven service within ANC services and the MOUs. Lessons learnt from programme implementation assisted the early development of ART services for adults and children in the province.[6] Following delivery, women were referred to the three MSF-supported ART sites in Khayelitsha, and new sites were established in 2003 in Khayelitsha, Langa and Gugulethu, in addition to secondary and tertiary facilities. When the national provision of ART was announced in 2004, organisations within the Western Cape had already changed priorities from demonstrating feasibility to targeting scale up and service integration.

Towards an integrated model of care for pregnant women requiring ART

In 2004, the Western Cape PMTCT protocols were changed to include CD4$^+$ count testing and referral of pregnant women with a CD4$^+$ count ≤200 cells/µl, or WHO stage 4, defining conditions for ART initiation. The treatment and care of pregnant women with advanced disease had been a part of global PMTCT strategy since 2002, yet there was little evidence on the best approach for implementing ART for pregnant women within vertical ANC services in resource-poor settings. Integrating the initiation of life-long ART in pregnant women into ANC services at a primary care level posed several challenges, including laboratory monitoring requirements, multiple ANC visits, linkage to postpartum ART, and clinical skills to manage both pregnancy and HIV.

Initially, pregnant women were referred to an existing ART clinic before delivery. However, many women failed to link to care or did not receive ART timeously. Patients also complained of the burden of additional visits to fetch their treatment, as well as of transport challenges. MSF thus began a pilot project to initiate eligible pregnant women on ART within two Khayelitsha MOUs in December 2004. This provided a fast-track system that streamlined services for providers and clients, and allowed late presenters to be initiated on ART within a week. Incorporating ART services within the ANC service was uncommon at the time, but it decreased loss to follow-up and limited delays by removing complex referral processes between facilities. Pregnant women with a CD4$^+$ count ≤200 cells/µl were fast-tracked for ART through weekly preparation visits, which included intensified adherence counselling and routine ART work-up. MSF trained and supported a midwife, an enrolled nurse, counsellors, and an outreach team of two obstetric medical officers provided by MSF and Mowbray Maternity Hospital (MMH).[7]

Implementation of NIMART in pregnancy

There were a number of challenges associated with the provision of ART within MOUs, including staff shortages and turnover that required human resource planning and training. Visiting community obstetricians from MMH did not get involved in ART provision, as few were experienced in prescribing ART. The integration model demonstrated functional separation, as a vertical ART initiation service was provided by a medical officer in a separate room in the MOU on specific days of the week.

Midwife-managed ART initiation had been the objective of the integrated MOU model, but it took six years to achieve this, despite well-managed and effective nurse-driven ART services at adjoining ART clinics. Staff saw the provision of ART at the ANC consultation as an extra task to perform in an already busy service. However, a different approach was required when new national guidelines were released in 2010. The CD4$^+$ threshold for eligibility for ART was raised (to 350 cells/µl), thus increasing the proportion of women who qualified for ART in pregnancy. This required task shifting and extending the prescribing capacity of midwives from dual regimens to providing ART.

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Following a successful pilot of nurse-driven ART in Lusikisiki and Lesotho, where there was a scarcity of doctors,[8] MSF partnered with the PGWC to implement a nurse-initiated management of ART (NIMART) mentorship programme in Khayelitsha in December 2011, with the first NIMART-trained midwives providing ART at the Site B MOU in May 2012. Early on, midwives were initiating 95% of clients within a week of first presentation.[9] There was strong support from midwives, and facility, programme and sub-district managers, and HIV integration and NIMART became policy. Midwives were excited by the NIMART training: 'For me, NIMART is very interesting, in that it's not something you do as a midwife. It puts you on another level. You see a patient; you diagnose and manage them. This is not what I was doing in the labour ward. I learnt a lot – about HIV, the drugs, everything.'

Implementing Option B+ in Khayelitsha

The announcement on World AIDS Day in 2012 that South Africa would shift from Option A (AZT for women with a CD4$^+$ count >350 cells/µl) to Option B (ART for all pregnant and breastfeeding women irrespective of CD4$^+$ count), highlighted the importance of NIMART mentorship for nurse midwives and ANC nurses. In July 2013, the Site B MOU in Khayelitsha implemented Option B+ (life-long ART for pregnant and breastfeeding women), including fixed-dose combinations, a new counselling model to support same-day initiation, and more attention to viral load (VL) monitoring in pregnancy, using VL as a predictor of transmission.

The rationale behind the introduction of Option B+ was not only to prevent the transmission of HIV to the infant, but to create an entry

point for lifelong ART care for women and their families. With this change, the linkage of HIV-exposed infants to care, retention in care for mothers receiving ART, as well as the provision of services which cater for male partners' needs have become even more of a priority. The implementation of Option B+ has been remarkably smooth. Since 1 July 2013, an average of 70 - 80 women have been initiated on ART monthly at the Site B MOU, and less than five women have refused to initiate treatment during this time. The fixed-dose combinations (FDCs) have made it easier for both staff and women. The adaptation of adherence counselling has led to shorter sessions that allow for same-day initiation, with increased post-initiation counselling being piloted in Khayelitsha. Despite the increased workload, midwives feel empowered and are passionate about their new role: 'Nowadays we manage their pregnancy and we also manage their HIV. I'm so committed that I don't care if I'm the one who leaves last – I don't mind. As long as I leave after seeing that every women who is eligible is initiated.'

The new challenge is to retain women on ART and achieve sustained virological suppression. An evaluation of the Option B+ programme is underway to study these outcomes. As more women who enter ANC services are already receiving ART (a quarter of the monthly new ANC attendees with HIV), an adapted model to prevent, detect and manage treatment failure is needed.

Conclusion

A large part of the success of the PMTCT programme in Khayelitsha has been due to progressive provincial policies, and a successful partnership between the provincial and local authority health services, academic institutions and non-governmental organisations such as MSF and the TAC, as well as dedicated managers and staff. Khayelitsha is a severely disadvantaged and resource-limited area, and yet the PMTCT programme has remained at the forefront of innovation and has evolved in line with advances in global best practice in ART care. There is hope that in the not-too-distant future, paediatric HIV infection will become a disease of the past, read about in textbooks.

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