

HATiP

HIV & AIDS Treatment in Practice

Issue 86 | 12 June 2007



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Audit of high infant mortality in Durban hospitals illustrates delivery gap remaining for PMTCT and paediatric ART programmes

The South African PMTCT and paediatric ART programmes are failing to reach many children at risk of HIV according to an audit of paediatric deaths in Durban's four regional hospitals presented by Dr Videsh Naidoo of King Edward VIII Hospital at the 3rd South African AIDS Conference in Durban last week.

Most of the deaths in the Durban hospitals were attributed to HIV — which should not be unexpected given the high antenatal HIV prevalence in the region. And yet, for roughly three quarters of the children's deaths, there was no information in the hospital records to indicate whether they or their mothers have been provided PMTCT services. Furthermore, only a small minority (of the children or mothers) received ART — despite clear evidence of advanced HIV disease.

"This serves as a reality check on the state of healthcare for our children," said Dr Naidoo. "A radical and innovative strategy is needed to improve the access of children and their parents, which is very important, to both PMTCT and HAART programmes."

While some presentations at the meeting suggested that there is indeed a low rate of coverage for the PMTCT programme, this could be the result of poor data collection and reporting practices. Nevertheless, this could impact the quality of support and follow-up provided for HIV-exposed children and their parents. In the end, it could be the poor integration of PMTCT, ART, antenatal and postnatal care that resulted in many of these deaths.

The city at the epicentre of AIDS

Durban is the largest city in KwaZulu Natal (KZN), the South African province with the highest antenatal HIV prevalence, around 37.2% according to one recent surveillance study (Rollins, AIDS 2007).

More than a quarter of Durban's population, around 900,000 out of 3.2 million people, are under the age of 15. Given the high prevalence of HIV, it is likely that many of these children are either HIV-infected or HIV-impacted — since even when there is not HIV transmission, maternal mortality rates due to HIV are very high. In fact, "HIV/AIDS accounts for more than 50% of the non-obstetric causes of maternal deaths," said Professor Nigel Rollins of the University of KZN during one of the conference plenary sessions.

As a result, infant and child mortality has also been on the increase both in the province and country as a whole since the epidemic began.

"We have high and rising level of under 5 mortality and morbidity," Dr Donna Jacobs-Jokhan said during a session on PMTCT. Dr. Jacobs-Jokhan is the medical director of University Research Co., which directs quality assurance for the PMTCT programme in five South African provinces. "In South Africa, 65% of the all paediatric [hospital] admissions are thought to be HIV-related," she said. And according to UNICEF estimates, without HIV/AIDS, the under 5-child mortality between 2002-2005 in South

Africa would probably have around 43 per 1000 births, but because of HIV, it is now about 74 per 1000 births.

The contribution of HIV to mortality is greater in KZN. "In 2005, it was shown that HIV accounts for 21.5% of the childhood deaths in the Western Cape and 50.1% of the childhood deaths in KZN," said Dr Jacobs-Jokhan.

To try to address this crisis, the single-dose nevirapine (sdNVP) PMTCT programme was piloted in some clinics in 2001 and then rapidly scaled up across the country. And over the last few years, paediatric ART programmes have also been established — especially at the major hospitals that provide specialist paediatric and obstetric care.

Durban has four: King Edward VIII Hospital, Mahatma Gandhi Memorial Hospital, RK Khan Memorial Hospital, and Prince Mshyeni Memorial Hospital. Each have established PMTCT and paediatric ART programmes, with 1691 children (approximately 17.6% of those qualifying for treatment) on ART at these facilities as of March 2007.

But the achievement of scaling up these programmes could obscure the treatment gap that yet remains.

The audit

Dr Naidoo and colleagues performed an audit of the child mortality at the four Durban hospitals to see to what extent children that died had had access to PMTCT services including the provision of sdNVP, whether they had at least started the process towards receiving ART for their own treatment — as well as whether their parents' health had been assessed and provision was made for ART.

A retrospective chart analysis was performed collating data for all the paediatric deaths at the four hospitals from January 1st, 2006 onwards. A project called the "Child Healthcare Problem Identification Programme" (CHIP) was also introduced into each hospital, which included a standardised mortality audit form.

The resulting data were compiled and analysed for correlations between infant/child deaths and gender, age ranges, weight and nutritional status, who was their primary caregiver, the well being of either parent, the child's HIV status (based upon test result and or clinical staging), provision of ART (for both mother and child), provision of cotrimoxazole prophylaxis and reported participation in the PMTCT programme. In addition, the analysis included an assessment on the documentation available for the children.

Results

A total of 875 deaths from 2006 and early 2007 were analysed, representing over 90% of the paediatric deaths from three of the hospitals (complete data are not yet included from the fourth site, and the period reviewed is not yet consistent across the four sites). 53% of the deaths were in male children, 47% female.

63% of the deaths were among infants (up to one year of age). But despite the fact that these deaths occurred well after the establishment of the PMTCT programme, 72% of the patient records contained *no information* as to whether PMTCT services had been provided. Among the quarter whose mothers did access the PMTCT programme, 24% of the mothers had tested negative, while 33% receive sdNVP prophylaxis. 43% did not.

HIV test results were available for 57% of the children. Of these, 52% had tested positive, 10% negative, and another 38% were HIV-exposed (had maternal antibodies to HIV but were not HIV PCR positive at the time of testing).

52% of the children who passed away had not been clinically staged. "Please note that clinical staging is the quickest and easiest way to determine an entry into ARV therapy, it can be done in the

first 10 minutes that you see a child,” said Dr Naidoo. But he said that after reviewing the cases with the doctors, it became apparent that about 30% of these cases were clinically symptomatic for HIV – and thus should have been staged.

Overall, 63% of all the deaths analysed were clinically symptomatic for HIV. Of the 419 children who were staged, 91% were categorised as having advanced HIV (WHO stage 3 or 4 disease). 60% of all the deaths were classified as being underweight (at least below the 3rd centile). More than half of these even had kwashiorkor or marasmus – severe malnutrition that has become extremely rare in middle-income countries without an AIDS epidemic.

“But despite the overwhelming clinical stigmata of advanced HIV disease, 60% [of 595 children] who were assessed for the need for ART were not on the medication at the time of their deaths,” said Dr Naidoo.

In addition, information on the wellbeing of parents was available for less than half of the mothers, and only 75% of the fathers.

“Whilst mothers are the predominant caregivers, assessment of their wellbeing remains poor, with 60% of those mothers assessed for HAART not yet accessing it. Father’s are largely being ignored,” said Dr Naidoo.

“Despite the overwhelming burden posed by the HIV pandemic, documentation of the first vital steps for access to intervention strategy (PMTCT and HAART) remains very poor... The assessment of the deaths at the four major hospitals in Durban confirms what we all know, the relatively high burden of disease, but despite the established PMTCT and ART programmes, the majority of children dying in Durban’s regional hospitals at this time appear not to be accessing these interventions... In many ways, this represents the failure of the system,” he concluded.

Other studies also suggest either poor HIV programme coverage or poor data collection

While it may not be entirely fair to judge the overall effectiveness of the PMTCT and paediatric ART programmes by the failures (infant deaths), the study does illustrate the likely outcome when the programmes fall short of their mark. And this is not the first study to suggest that there is a significant gap between real and expected performance for these programmes. At the World AIDS Conference last year,

<http://www.aidsmap.com/en/news/74A5B372-0FAF-4EB1-8825-F84DDAB7D367.asp>>Prof. Rollins and colleagues reported that

despite the PMTCT programme, HIV surveillance data gathered at immunisation clinics in KZN found that 20.8% of HIV-exposed infants had become HIV-infected. Based upon data from clinical trials, transmission rates should have been much lower (around 11.9%), if every woman with HIV had been identified and every HIV-positive pregnant woman and exposed child had been given antiretroviral prophylaxis.

Other reports at the conference suggested that, nationwide, the coverage of the PMTCT programme is shockingly low – only around 15-17% according to Department of Health data. But there was some controversy surrounding whether these figures are correct, or at least current.

“When we heard those figures, those of us working in the PMTCT programme sat up thinking, ‘that can’t be right.’ I think that this is largely a data collection problem that needs to be addressed at the facility level,” said Dr Jacobs-Jokhan.

In fact, she presented data from the quality assurance project (QAP) at 106 supported facilities in five provinces (in the Eastern Cape, KZN, Limpopo, Mpumalanga and the Northwest Province) showing that HIV testing uptake had improved from 55% in the first quarter of 2006 to 71% in the first quarter of 2007 for all first antenatals. Likewise, sdNVP prophylaxis uptake among mothers and/or infants testing positive also improved dramatically over this period – to 100% for the live births whose mothers had a HIV-positive result (but somewhat lower uptake among the mothers themselves during delivery). However, taking into account the mothers who did not accept an HIV-test, the actual sdNVP prophylaxis uptake among infants at risk was 80% and 74% in the mothers.

Likewise, Dr Dhayendre Moodley of the Nelson Mandela School of Medicine said that among those mothers who test positive in a KZN survey at QAP supported sites, uptake of antiretroviral prophylaxis was now rather high, with around 83% for mothers and 95.4% for their infants according to a KZN survey. However, she noted that participation in the PMTCT programme had been poorly reported in the registers.

Getting to the bottom of whether the DOH PMTCT uptake figures are accurate or whether these QAP figures on uptake are closer (at least the baselines) to what is seen in the rest of the country could have important implications for the complexity and quality of the interventions offered to pregnant women. For instance, there are more effective prophylaxis regimens than sdNVP (including adding AZT during pregnancy, or possibly the addition of an AZT/3TC tail to decrease the chance of nevirapine resistance developing). Previously, the emphasis has been on improving the coverage of the programme rather than tweaking the intervention offered, and yet, the QAP figures of coverage and uptake are so high, that it suggests that the programme is ready to do more, or at least soon could be with the introduction of quality improvement.

Indeed, the QAP-supported PMTCT sites already promote a complete package of other services to promote holistic care for all pregnant women, including offering STI and TB and OI screening and management.

Improving integration of services

To truly improve child survival, Prof. Rollins stressed that there needs to be better integration of PMTCT, ART and maternal and child health services across the continuum of care – starting with testing and prevention services.

Receipt of PMTCT services is of course dependent upon the mother’s choice to participate in the programme, including, first and foremost, her willingness to be tested for HIV. Refusal to consent to the HIV test remains one of the biggest hurdles for sdNVP uptake.

More has to be done to encourage women to learn their status, said Prof Rollins, and to take advantage of the opportunity that antenatal testing offers. According to another study presented at the meeting, offering mothers an HIV test again (in the labour wards postpartum), could provide a last chance to deliver sdNVP to her infant – and this offer was accepted by about 60% of women (Theron).

Prevention services among those women who test HIV-negative during pregnancy also need to be improved. In Dr Rollin’s study, the rates of mother to child transmission were extremely high among women who reported that they were uninfected (which indicates they may have seroconverted after antenatal screening).

However, PMTCT is not limited to the administration of sdNVP – the use of ART among those who have low CD4 cell counts can have

an even greater impact upon transmission rates. Dr Jacobs-Jokhan stressed the QAP programme encourages clinical staging and CD4 testing of women who test positive, and referral of those who qualify for ART. But experience in other settings suggests that there can be difficulty integrating ART and PMTCT programmes in practice — which means that few of these women indeed start on ART in time. Notably, only 5 out of 535 pregnant women included in the KZN survey were actually on ART at the time of delivery — when surely more of them must have qualified for ART.

Women who have CD4 cell counts less than 200 “represent about 12-15% of all HIV-infected pregnant women,” said Prof Rollins, “but they account for 40-50% of all mother to child transmissions.” Furthermore, if the mother dies of HIV, all of her children are three to four times more likely to die — so getting mothers onto treatment is essential.

And PMTCT cannot stop at delivery. After childbirth, providing counselling and support on infant feeding choices and proper follow-up for both the child and its mother are extremely important.

“We need to bridge that gap between antenatal care and postnatal services,” said Prof Rollins. Improved documentation of participation in PMTCT (starting with integrating mother and child health cards) could be crucial for continuity of care or to enabling mothers and children to get into care again.

But poor record keeping could effectively derail the programmes good intentions to provide improved support, follow-up and continuity of care for both child and parents — especially when they go to larger hospitals such as those Dr Naidoo described. Inadequate documentation could also have been one of the contributing factors for why so few of the children in the Durban hospital audit were able to access ART in time before they died.

It is not absolutely clear from Dr Naidoo’s study that the poor documentation was the fault of the antenatal clinic/PMTCT side (although this might be inferred from both the QAP presentations and the low reported DOH figures for PMTCT coverage in the country) or whether the child’s history was poorly transferred when he or she was admitted to the hospital.

“Regardless, the patient’s notes are the working document that the management is based on, and failure to record or transfer information from the Road to Health Card [child health card] to the patient notes is a failure to perform a proper clinical examination and assessment of every child,” said Dr Naidoo. However, he stressed that the complete absence of any information about the child’s receipt of PMTCT services, “was the audit’s most striking finding of all.”

At the very least, the audit shows that some children are falling through the cracks when PMTCT, maternal and child health services

and the ART programme are not adequately coordinated — and that integration may be easier said than done.

According to Prof Rollins, if PMTCT targets are to be met, integrated services will need to be planned and managed.

“We need to think about prioritisation and the dedication of resources. Integration has been the new mantra for the last several years but we don’t know how to integrate. We don’t need just a framework, we need detailed implementation plans on how to put it together at the district level,” he said.

But he stressed that improved mother and child health should be the endpoint for these programmes, not just delivery of sdNVP prophylaxis (or whatever the particular prophylactic regimen being used). “Survival, and not just the avoidance of transmission should be our paradigm for the future,” he concluded.

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about HATiP

A regular electronic newsletter for health care workers and community-based organisations on HIV treatment in resource-limited settings.

The newsletter is edited by Theo Smart (Cape Town) and Keith Alcorn, NAM’s Senior Editor (London).

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