TREATMENT AND RESEARCH OPTIONS FOR PAEDIATRIC HIV INFECTION IN SOUTH AFRICA: TOWARDS IMPROVING CARE

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This satellite meeting at the 2nd South African AIDS Conference was organised to facilitate and inspire paediatric networking opportunities within South Africa and Africa. The meeting was a collaborative venture between recipients of the Elizabeth Glaser Pediatric AIDS Foundation International Leadership Award (Clive Gray and Tammy Meyers), the African Network for the Care of Children Affected by AIDS (ANECCA) and the Institute of Healthcare Improvement (IHI). The treatment needs of many HIV-infected children in South Africa are not being met, the antiretroviral rollout for children lags behind that of adults, and there are many unanswered clinical and scientific questions that should be addressed by local researchers and scientists to improve paediatric care. The overall purpose of this satellite meeting was to introduce clinical and research networks that are working towards improving the care for HIV-infected children in Africa. More specifically, the objectives of the meeting were:

- to promote awareness pf paediatric networks functioning in Africa
- to link seemingly disparate areas of knowledge around treatment and research in immunology and health care, and
- to facilitate networking through established African paediatric networks.

The satellite meeting was chaired by **Brian Eley**, University of Cape Town, and **Clive Gray**, National Institute for Communicable Diseases. Four networks were introduced at the meeting: African Network for the Care of Children Affected by AIDS (ANECCA, **www.rcqhc.org**); the Institute for Healthcare Improvement (IHI, **www.ihi.org/IHI/Topics/DevelopingCountries/Africa/**); The Baylor International Pediatric AIDS Initiative (**www.bayloraids.org**); and Thuiso Ka Tsebo, an 'Enrichment through Knowledge' programme focusing on paediatric immunology for South African paediatricians (**www.immunopaedia.com).**

Dorothy Mbori-Ngacha, Department of Paediatrics, University of Nairobi, introduced ANECCA as a pan-African network of paediatricians working towards better treatment options and care of all children infected and affected by AIDS. A handbook on paediatric AIDS in Africa, pubished by the Regional Centre for Quality of Health Care, has been co-authored by 27 clinicians from nine African countries and is available from the web address above. The handbook mirrors the objectives of ANECCA by providing information on all aspects of paediatric AIDS, ranging from the epidemiology, pathogenesis and natural history of HIV in children to antiretroviral drug regimens and doses in paediatric practice, aimed at medical students and their lecturers, nurses, clinicians, community health workers and other service providers in resource-poor settings. For further information on ANECCA, contact details are on the web site or email: **dtindyebwa@rcqhc.org**, **ntumwesigye @rcqhc.org** or **beley@ich.uct.ac.za**.

Pierre Barker from the Institute for Healthcare Improvement gave a comprehensive overview of the activities of IHI in South Africa and pointed out that despite a successful countrywide programme to identify and treat HIV-positive mothers and their newborn babies with antiretrovirals, there has been a complete failure in most areas to track, identify and treat infected infants during the first year of life. As a result, infants are being identified late for treatment or are dying in the first 18 months of life. Preventable errors such as mixed feeding have mitigated against the effects of the prevention of mother-to-child transmission (PMTCT) programme, and have increased infection rates. Health-provider fear of treating infected children, and lack of training and experience with paediatric HIV/AIDS outside the major metropolitan areas, means that infants and children with this disease are virtually ignored in many rural areas. In the Western Cape, 73% of infants and children who are on antiretroviral therapy (ART) are being cared for at three academic hospitals in Cape Town. The proportion of children being cared for at these urban, academic facilities has not changed over the past year, suggesting that current strategies to spread paediatric care outside tertiary care centres are not working. In contrast to the realities of mixed adult/paediatric practices in provincial and rural areas, paediatric care in the major academic centres is isolated from adult services, ignoring the need for a family-based approach to a paediatric disease that by definition will include at least one co-infected adult family member.

A paediatric learning collaborative can identify and solve paediatric-specific HIV/AIDS issues at the front lines of care,

and provide training, knowledge and support to parts of the healthcare system located away from the academic centres. The development of district and regional networks will allow a comprehensive approach to HIV/AIDS management that includes PMTCT, diagnosis, identification of affected family members, referral, initiation of treatment, and chronic care.

FOCUS OF THE LEARNING NETWORK

1. Provide training and expertise for paediatric HIV/AIDS care in all regions of South Africa. Currently the bulk of paediatric care is taking place at urban academic paediatric-specific centres. These centres have developed considerable expertise in initiation and management of paediatric HIV/AIDS, and this knowledge can be transferred through training and support to urban and rural regional sites that do not as yet have this expertise through development of regional learning collaboratives. Regional outreach teams can provide technical expertise within the framework of collaborative networks supported by IHI (see below).

2. Develop up- and down-referral networks for comprehensive care. Services providing PMTCT, early infant HIV diagnosis, and chronic care for HIV-infected infants and children need to be connected or integrated to ensure timely diagnosis and treatment.

3. Develop a family-focused approach. The needs of paediatric HIV care can best be met within the context of family-based care. While this should be the goal of all paediatric HIV/AIDS care, it is particularly applicable to the smaller centres and rural sites where paediatric services are not segregated from adult care.

ESTABLISHING A LEARNING COLLABORATIVE

Since July 2004, the IHI has been assisting a number of rural and urban sites within the South African state-run health care system to improve systems of care within the National Comprehensive HIV/AIDS and ARV programme. The IHI is currently active in five provinces covering rural, urban, adult and paediatric practices. The core strategy is to bring together health care workers from multiple sites to work with a common purpose to improve their own health care systems.

In the IHI's Breakthrough Series (BTS) model, multiple sites are brought together with a common purpose and develop a set of strategies that are tested (using rapid cycle feedback method) to reach their goal. The improvement process is accelerated by spreading local innovations through structured regular interactions (conference calls, group meetings, visits by improvement advisors, listserve postings, etc). A crucial element is the spread of knowledge through regular reporting of common measures from each of the participating centres to a site that can be accessed by all the participants.

The improvement projects build on the basic training and knowledge of the caregivers and the guidelines contained in the national HIV/AIDS programme. Through a structured series of small interventions, designed by the local participants themselves, the health care system improves from the ground up, and capacity expands to accommodate local needs, mostly through more efficient use of existing resources. During the process, well-proven improvement methods are learnt by local health care workers with the intention that each project will be self-sustaining and leading family-based HIV/AIDS care in their area 18 months after start-up.

NETWORK STRUCTURES

Three types of network can contribute to improved paediatric HIV/AIDS care in South Africa:

1. District-wide collaboratives. The IHI is currently supporting district-wide networks in five provinces for sites that are undertaking both adult and paediatric care. In this format primary, secondary and tertiary care sites are connected through learning sessions and system improvement meetings with participation from district leaders and all components of the health care teams.

2. Regional paediatric-specific networks. In Gauteng/North-West provinces and the Western Cape, IHI is supporting regional paediatric outreach learning collaboratives for providers of paediatric HIV/AIDS care. These initiatives are led by units from Harriet Shezi/Coronation hospitals and Tygerberg Hospital, respectively.

3. Nationwide networks. The lessons learned from paediatric networks around the country can be spread rapidly through a structured process which includes common aims, a common approach, and common reporting of agreed measures of performance of paediatric HIV/AIDS care. This sharing of information and improvement of the system of paediatric care can be fostered through a programme of meetings, conference calls, internet listserves and electronic media.

For further information on IHI's activities in South Africa, contact Pierre Barker (**pierre_barker@med.unc.edu**).

Peter Navario from the Baylor College of Medicine gave a comprehensive review of the Baylor International Pediatric AIDS Initiative activities in Africa. BIPAI core competencies include care and treatment, education and training, and research. Baylor College of Medicine began paediatric HIV training in Africa in 2000. In 2003, Baylor partnered with the Government of Botswana to open the Botswana-Baylor Children's Clinical Centre of Excellence (COE) in Gaborone. It provides care and treatment for over 1 200 children and 80 families in Botswana. In 2004, BIPAI was subcontracted by the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) to provide paediatric HIV technical support in the four Project HEART countries of Tanzania, Zambia, South Africa and Côte d'Ivoire. Project HEART is funded by PEPFAR. Additional details on the various BIPAI activities are included below.

CARE AND TREATMENT

At present, the Baylor Network provides outpatient care and treatment to HIV-infected children through its clinics in Houston, Botswana, Romania, Libya and Uganda. In all, there are approximately 2 500 children on ART in the Baylor Network clinics. New paediatric clinics in Swaziland, Lesotho and Malawi will join the network in late 2005/early 2006.

TRAINING

Since 2000, Baylor has provided HIV/AIDS training to health professionals in 20 African nations. In addition to Project HEART – the largest stand-alone training programme within BIPAI – health professional training is ongoing in Uganda, Swaziland, Lesotho and Botswana. Baylor uses different models for health professional training:

1. Didactic training. One week of comprehensive introdutory training in paediatric HIV care and treatment. In addition to lectures, the training team spends time working side-by-side in clinics with the learners in order to reinforce lessons learned in the didactic sessions.

2. Attachment training. Health professionals spend 1 - 2 weeks (typically) training with experienced staff at the COE in Botswana.

3. Preceptorship training (clinical mentors). BIPAI paediatricians spend an extended period of time (typically for several months) working with sites on training and systems to ensure high-quality paediatric HIV care and treatment.

Baylor provides the following training materials to learners as well as to other organisations that requires training materials:

- *HIV Curriculum for the Health Professional* (3rd ed., 2005)
- Paediatric ARV dosing charts
- Growth charts
- *Options for Children: A Guide to ART*
- Educational videos: 'Kids to Kids', and 'So now you know. Now what?'.

Finally, Baylor actively pursues both clinical and psychosocial research within the network in order to advance knowledge in paediatric HIV/AIDS. In Botswana, the BANA II trial is looking at efficacy and feasibility of structured treatment interruptions in children using a Kaletra-based regimen. At the time of presentation, approximately 200 children were enrolled. The enrollment goal for the study is 600. In addition, numerous psychosocial research projects have been undertaken, are ongoing, or are proposed.

For further information concerning the Baylor International Pediatric AIDS Initiative, contact Peter Navario in Cape Town on **navario@bcm.edu.**

The fourth network, presented by **Clive Gray** at the meeting, was Thuiso ka Tsebo (Enrichment through Knowledge), a programme funded through an Elizabeth Glaser Pediatric AIDS Foundation International Leadership Award. This is a collaborative venture based on understanding the immune system of HIV-uninfected and infected children and using this knowledge to implement a deeper understanding of treatment and prevention options. The structure of Thuiso consists of a collaborative training programme (CTP), known as 'IMMUNOPAEDIA' that will foster the themes of Communication, Collaboration and Connectivity through several interfaces. Implicit in establishing communications, is to institute collaborations between paediatricians and scientists and to create connectivity in seemingly disparate areas of knowledge. This will be thought of as a bi-directional cycling phenomenon, where multiple reiterations of the 3C themes will be advocated (Fig. 1).

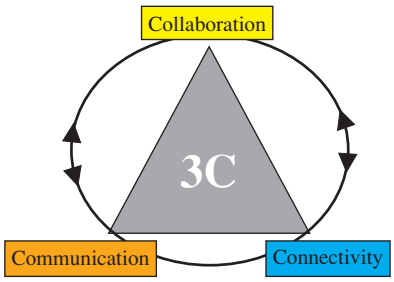

Fig. 1. The bi-directional collaborative programme of Thuiso ka Tsebo aiming to foster the 3Cs: Collaboration, Connectivity and Communication between paediatricians and science.

Paediatric immunology is not a recognised discipline in South African medical schools and is therefore not taught as a discrete module. The 'how' and 'what' is therefore important to understand from the perspective of supplementing and reinforcing knowledge gaps, which is the one of the main aims of Thuiso ka Tsebo. Currently, the premise in appreciating knowledge gaps in paediatric immunology is rooted in our understanding of the immune system in HIV-infected and uninfected adults. It may be wrong and flawed to translate knowledge from the adult to the child – especially in understanding what may be required from HIV vaccine strategies. One of the aims of the IMMUNOPAEDIA programme of Thuiso is therefore to collate knowledge of the neonate and child immune system into a format that can be used for teaching and dissemination of practical knowledge to paediatricians. Most of the practising paediatricians in South Africa qualified from medical schools and specialised in a paediatric discipline before tertiary educational changes. Approaches were content-driven and didactic and founded on traditional methods of teaching from 'experts'. Thuiso is planning content with the aim of facilitating understanding and hence extended knowedge about the immune system through an e-learning web site targeting registrars and paediatricians and will be launched in January 2006. The prototype web site can be found at **www.immunopaedia.com**.

Thuiso ka Tsebo is currently at the stage of performing a needs assessment among paediatricians within South Africa of:

- what is the knowledge of immunology
- how web-based learning can facilitate immunology knowledge, and
- what are the perceived links between immunology and paediatric medicine pertaining to HIV.

For more information on this programme, contact Clive Gray on **cgray@nicd.ac.za**.