

BAYLOR COLLEGE OF MEDICINE CHILDREN'S FOUNDATION- UGANDA

Annual Report
2005/06



BAYLOR
COLLEGE OF
MEDICINE
Children's
Foundation
UGANDA

VISION

“To become a paediatric & adolescent hiv centre of excellence through service delivery, training & research in uganda & beyond”

MISSION STATEMENT

“To **PROMOTE, PROTECT** and support the health of HIV exposed and infected **CHILDREN** and **ADOLESCENTS** of Uganda such that they can **ATTAIN SELF FULFILMENT**; to **TRAIN HEALTH PROFESSIONALS** ;to carry out **RESEARCH** and to excel in all we do with dedication”



Baylor College of Medicine Children's Foundation-Uganda

Paediatric Infectious Diseases Clinic, Mulago Hospital



Annual Report 2005/06

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Acknowledgments

We at the Baylor College of Medicine Children's Foundation - Uganda (Baylor - Uganda) are proud that so many people have contributed to our vision and creating our legacy. We acknowledge you all; the Department of Paediatrics and Child Health of Makerere University/Mulago Hospital, Mulago Hospital Administration, Centers for Disease Control and Prevention (CDC), our cherished partners, Baylor International Paediatric AIDS Initiative (BIPAI) our patients and their caretakers and the staff of Baylor - Uganda. The staff deserve our deepest appreciation, heartfelt thanks and greatest admiration, for they never get tired serving the increasing numbers of patients.

With your support Baylor College of Medicine Children's Foundation - Uganda has made a difference to the face of paediatric HIV/AIDS in Uganda. Through all your efforts and dedication, we will continue to strive to become a centre of excellence.

In a special way, we must acknowledge the children affected and infected with HIV/AIDS in Uganda. Their courage and suffering, the perseverance of those that care for them as they face untold difficulties, are the greatest reasons for us at Baylor - Uganda to continue to find ways to inspire them never to give up.



A handwritten signature in blue ink, appearing to read 'A.L. R.' followed by a circular flourish.

Dr. Adeodata Kekitiinwa Rukyalekere

Executive Director

Baylor College of Medicine Children's Foundation - Uganda

Senior Consultant Paediatrician at Mulago Hospital



Acronyms

AIC	AIDS Information Centre
ANECCE	African Network for the Care of Children with HIV/AIDS
ART	Antiretroviral Therapy
ARV	Antiretroviral
Baylor - Uganda	Baylor College of Medicine Children's Foundation - Uganda
BCM	Baylor College of Medicine
BCMFC	Baylor College of Medicine Children's Foundation - Uganda
BIPAI	Baylor International Paediatric AIDS Initiative
BMS	Bristol-Myers Squibb
CAI	Child Advocacy International
CBVCT	Community Based Voluntary Counselling and Testing
CDC	Centers for Disease Control and Prevention
CDPTC	Child Development and Play Therapy Centre
DBS	Dried Blood Spot
DNA	Deoxyribonucleic Acid
EGPAF	Elizabeth Glaser Paediatric AIDS Foundation
FY	Fiscal Year
HAART	Highly Active Antiretroviral Therapy
HBVCT	Home-Based Voluntary Counselling and Testing
HHP	Home Health Programme
HHW	Home Health Worker
HHV	Home Health Visit
IEC	Information, Education and Communication
KCC	Kampala City Council
LTF	Lost To Follow-up
MJAP	Mulago-Mbarara University Teaching Hospitals' Joint AIDS Programme
MU-JHU	Makerere University - Johns Hopkins University Collaboration
PAC	Paediatric AIDS Corps
PCR	Polymerase Chain Reaction
PEPFAR	President's Emergency Plan for AIDS Relief
PIDC	Paediatrics Infectious Diseases Clinic
PMTCT	Prevention of Mother to Child Transmission of HIV
PREFA	Protecting Families Against HIV/AIDS
PSI	Population Services International
SOP	Standard Operating Procedure
UPC	Unannounced Pill Count
UTAP-GAP	University Technical Assistance Programme – Global Assistance Programme
VCT	Voluntary Counselling and Testing



Highlights as of June 30, 2006

1. Testing and counselling

The number of individuals counselled and tested for HIV almost doubled, increasing from 3,646 to 5,221, with 38% testing positive.

2. Palliative care

A total of 3,754 children were served at PIDC and its satellite clinics. Of these, 2,589 children and families have received at least two bed nets each.

3. Antiretroviral drugs and services

Almost 800 children were started on HAART, raising to 1,466, the total number of children receiving HAART through Baylor - Uganda and its satellites. To improve on ART adherence, a computerised patient tracking system has been instituted.

4. Training

A total of 373 health professionals have been trained in comprehensive paediatric HIV care.

5. Staff development

Staff underwent short courses on customer care, Standard Operating Procedures and good clinical practice.

6. Capacity building

Baylor - Uganda spearheaded the initiation of HIV/AIDS clinics in Kampala City Council health facilities at Kawempe and Naguru and also strengthened PMTC linkage into care at the Mulago Hospital's postnatal clinic as well as Kawempe and Naguru.





Background

It was 1988 when Dr. Denis Tindyebwa, a Senior Paediatrician in the Department of Paediatrics and Child Health, got the vision to start a clinic for HIV-infected children at Mulago National Referral Hospital. From the beginning, HIV testing by serology and treatment were the only services offered at the clinic. Services were very basic, with poor record management and lack of organisational systems. In 2002, with the request of Dr. Tindyebwa, the Centers for Disease Control and Prevention (CDC) refurbished Ward 15 of Mulago Hospital to become the new Paediatrics Infectious Diseases Clinic (PIDC). The Department of Paediatrics and Child Health then appointed Dr. Adeodata Kekitiinwa as the first Clinic Director of PIDC. Since then, partners including CDC, the Academic Alliance (now Infectious Diseases Institute), Feed the Children Uganda, Child Advocacy International (CAI) and Paediatric AIDS Canada have all contributed significantly to the success of Baylor - Uganda, a true example of a successful public-private partnership.

Through contributions from partners such as Baylor College of Medicine (USA), the Infectious Diseases Institute (IDI) and Feed the Children Uganda, Wisconsin University (USA) and Paediatrics AIDS Canada, Baylor - Uganda staff led by Dr. Adeodata Kekitiinwa have strived to achieve the vision of the clinic. With improved and regular services, better client care and sustained drug supply including antiretroviral drugs, patient numbers in HIV care have grown to exceed 3,500. Antiretroviral treatment was introduced at the Baylor - Uganda in December 2003 with 250 children on Triomune sponsored through Paediatric AIDS Canada. In order to offer family care and also decongest the PIDC, three satellite clinics were opened in conjunction with other partners.

Since October 2004, the President's Emergency Plan for AIDS Relief (PEPFAR) through Baylor College of Medicine, USA awarded Baylor - Uganda a grant to provide the following services:

- HIV Testing and counselling
- Palliative care including basic HIV/AIDS health care
- Antiretroviral drugs and related services

The programme has now revisited its vision and offers a comprehensive HIV/AIDS care based on the Ten Point Programme at all its clinics. This Ten Point Programme (management plan) includes;

PEDIATRIC HIV Ten Point Management Plan

1. Early diagnosis of HIV infection
2. Growth and development monitoring
3. Immunizations - routine EPI & routine deworming
4. Nutrition education and supplementation - macro and micronutrients (Vitamin A & Multivite)
5. Aggressive treatment of acute infections
6. Prophylaxis and treatment of opportunistic infections PCP prophylaxis)
7. Psychosocial support and palliative care
8. Adolescent care and support
9. Mother and family care - MTCT plus
10. Antiretroviral therapy when available and indicated



Milestones

PIDC was officially opened on 13th December, 2003 by the US Secretary of Health and Human Services, Tommy Thompson in the presence of the CDC Director, Julie Gerberding and the Uganda Minister of Health, Hon. Jim Muhwezi. The CDC has maintained financial and technical support to the Baylor College of Medicine Children's Foundation - Uganda and we would like to acknowledge them.

In December 2005, a PEPFAR review team from the US selected PIDC Mulago as the best institution in offering paediatric HIV services

In September 2004, PIDC, through Baylor College of Medicine (BCM) under University Technical Assistance Programme (UTAP), received supplemental funds to support rapid scale-up of paediatric ARV programmes through the Department of Paediatrics and Child Health, Mulago Hospital/Makerere University. About 1,300 children received life-saving ARV drugs under this arrangement. Ms Sue Kelly is the Project Manager and Training Officer coordinating these activities. In collaboration with Baylor International Paediatric AIDS Initiative (BIPAI), Ms Kelly initiated the Training Programme at the PIDC including designing the five-day and three-day courses. Currently a new initiative in collaboration with Elizabeth Glaser Paediatric AIDS Foundation (EGPAF), Ministry of Health (MOH) and African Network for the Care of Children Affected by AIDS (ANECCA) has been developed to provide support supervision in different parts of the country. To date, 373 Ugandan health professional have been trained.

In August 2004, Dr. Jeannie Chang Pitter joined the PIDC as a Clinical coordinator from Baylor College of Medicine (BCM). Dr. Chang spearheaded development of patient tools and clinical standard operating procedures at the unit. Baylor - Uganda is proud to have shared the patient tools internationally in all the BIPAI network centres of excellence.

As PIDC continued to strive for quality HIV paediatric care, Mr. Albert Maganda was recruited to establish the data management system. Mr. Maganda worked for Case Western Reserve University for several years as

a statistician and he is excited by the challenges of developing a data management and information system in the next fiscal year.

In December 2005, a PEPFAR review team from the US selected PIDC Mulago as the best institution in offering paediatric HIV services. Thanks to the entire team at Baylor College of medicine Children's Foundation - Uganda that worked hard for these excellent results.



The US secretary of Health and human services, Mr. Tommy Thompson, (second from left), Dr. Julie Gerberding, the CDC director (extreme left), Mr. Jim Muhwezi, former Uganda Min. of Health, 2nd from right and Dr. Jack Luyombya, Head of Mulago Hospital Board of Directors, officiating at the PIDC opening.



The satellite clinic activities

In order to decongest the main clinic and to offer early infant diagnosis in a family care setting, Baylor - Uganda pioneered family-centred HIV/AIDS care at Kampala City Council Clinics, in September 2005 services were started in Kawempe and later Naguru. Baylor - Uganda was quickly joined by the Mulago-Mbarara Teaching Hospitals' Joint AIDS Programme (MJAP). In May 2006, in collaboration with TASO, Baylor - Uganda started offering family services at the Kanyanya TASO clinic. Together, Baylor - Uganda and MJAP provide comprehensive HIV care and support including antiretroviral therapy. In addition, clinical activities at the satellites are achieved through collaboration with Kampala City Council (KCC), Protecting Families Against HIV/AIDS (PREFA), Plan International, and AIDS Information Centre (AIC). As the satellites became busier, Dr. Hannifah Sengendo joined to replace Dr. Ezekiel Mupere, the initial Programme Coordinator who left for further studies. Dr. Sengendo now joins the team of motivated and hard-working health workers as a full time coordinator and specialist. Dr. Sengendo comes with a great deal of enthusiasm and is prepared to extend the vision of Baylor - Uganda into the satellite clinics. The trend at the satellites is no better than the general worldwide one where adults are enrolled rapidly into HIV/AIDS treatment programmes, leaving behind their children. It has been more challenging to reach and enroll children in these settings. Dr. Sengendo has an uphill task of making sure that all adults in care bring their children for HIV counselling and testing.

Baylor - Uganda consolidated its services, it was necessary to re-examine where we came from and where we would like to go. A consultancy firm was hired to help in developing a five-year strategic plan that will propel us into the future. The plan will be launched soon.

One of our adolescents, Brian Nganwa, was invited to deliver opening remarks at a recently completed international conference on Sexual and Reproductive Health Rights of PLWHAs, in Addis Ababa, Ethiopia

New initiatives

Among the new initiatives started at the PIDC, was hiring a full time teacher to keep the children busy while they wait for care and treatment. As children play or learn new reading and writing skills, parents watch with keen interest, a sign to show that a child is one of the reasons parents exist.



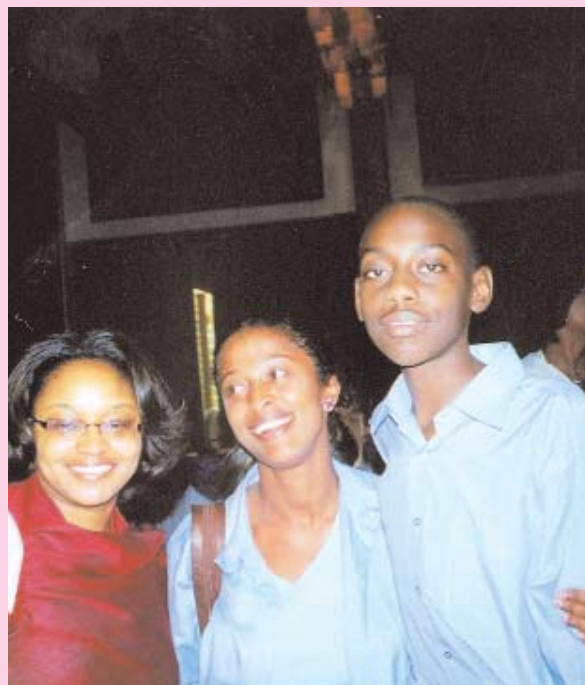
Teacher Jane Beyeza leads children through play at Baylor College of medicine Childrens Foundation - Uganda Ward 15

Community services

Baylor - Uganda strengthened its links with the community by offering community HIV testing and counselling to members of PIDC clients' families that would have found it difficult to bring children during working days. These activities are organised and mobilised by caretakers. As part of reducing stigma, parents have been trained to offer health talks at the clinics as patients wait to be seen.

Adolescent psychosocial group

With the growing number of adolescents at PIDC Mulago, the clinic started a support group with the support of the Bill and Melinda Gates Foundation. The aim was to fight stigma, promote adherence to therapy, provide sex education and provide opportunity for teenagers to socialise. One of our rising adolescents, Brian Nganwa, was invited to deliver opening remarks at the International Conference on 'Sexual and Reproductive Health Rights of PLWHAs', in Addis Ababa, Ethiopia, which took place between 27th-31st March 2006.



An adolescent client of Baylor-U receives a standing ovation for his presentation at an AIDS workshop in Addis Ababa

Family-based care

Noting that HIV/AIDS is a family disease, Baylor - Uganda pioneered a family-based clinic beginning August 2005. Clients were carefully chosen to benefit those who go for care both at PIDC Mulago and IDI or TASO. This initiative is yet another one where the IDI has collaborated with Baylor - Uganda in achieving its mission.

Under this arrangement, patients from the same family attend the clinic with a single appointment. It is hoped that with construction of a new building and availability of more space, this service will expand to cater for more families.

Baylor - Uganda pioneered a family-based clinic beginning August 2005. Under this arrangement, patients from the same family attend the clinic with a single appointment.

Monitoring and evaluation

During this fiscal year Baylor - Uganda introduced an excellent data management system to generate information for internal and external reporting. The information generated is already being used for planning purposes and accountability to stakeholders, including donors. The system has enabled management and staff to identify and learn from best practices. The clinic can do real time registration and enter real time appointments, enhancing the tracking of patients' lost-to-follow-up.

Twinning

Baylor College of Medicine Children's Foundation - Uganda is currently twinned to eight other BIPAI network sites. Following the successful hosting of the 3rd BIPAI network meeting at Speke Resort, Munyonyo in Kampala (May 5), key Baylor - Uganda staff travelled to Lesotho (November 2005) to learn and share experience with other BIPAI network members. Through this partnership, Dr. Sabrina Bakeera-Kitaka, an IDI fellow, has received training in microbiology, pathology and virology at Texas Children's Hospital. In addition, Dr. Betty Nsangi, an IDI-supported doctor, is pursuing



a Masters degree in Public Health at University of Texas. This will certainly improve the status of health care in Uganda as we target the future leaders of our clinic.

Partnership

Baylor College of medicine Children's Foundation - Uganda is a collaboration between Mulago Hospital Department of Paediatrics and Child Health, Makerere University Medical School, Baylor College of Medicine, Infectious Diseases Institute, Paediatric AIDS Canada, Feed the Children Uganda, University of Wisconsin and Child Advocacy International.

Looking into the future

Baylor College of Medicine, with a grant from Bristol-Myers Squibb (BMS), has started constructing a Children's Center of Excellence within Mulago Hospital Complex. The ground breaking function of the new site was held on the 30th June 2006 and Baylor Uganda was happy to host high powered delegations from all partners. The Minister of state for Health, Dr. Richard Nduhura officiated at the function. The clinic will feature modern facilities to test, treat and monitor children and their families, and will be an added resource to train Ugandan health professional in HIV care. Under the same initiative, Paediatric AIDS Corps (PAC), a programme of BCM and BMS, Baylor - Uganda will receive five physicians to help in rolling out paediatric HIV care and training. The impact of these PAC doctors will be enormous as Baylor - Uganda expands its services to the East and West of Uganda.



Ground breaking function: left to right; Director of Programs CDC-Uganda, Dr. Dona Kabatesi, Director of Operations CDC-Uganda, Harold Rasmussen, Director Mulago Hospital, Dr. Edward Ddumba, BIPAI Vice President International Affairs, Mr. Mike Mizwa, Minister of state for Health, Dr. Richard Nduhura, Senior Director, Medical Research Bristol-Myers Squibb, Dr. Sebastian Wanless, Executive Director, Baylor-Uganda, Dr. Addy Kekitiinwa, Head of Pediatrics Department (Mulago Hospital, Dr. Philli pa Musoke, Dean of faculty of Medicine, Makerere University Dr. Nelson SSewankambo.

Effective scale-up of paediatric HIV care and treatment services requires seamless integration of prevention, care, and treatment services and this will be achieved through:

- Strengthening prevention of mother-to-child HIV transmission (PMTCT) interventions
- Linking PMTCT services to HIV care
- Expanding access to home-based voluntary counselling and testing
- Establishing family-centered services

In addition, an expanded training framework with emphasis on regional support supervision will be implemented.

The Baylor - Uganda leadership is committed to building strong partnerships as part of an aggressive campaign to accelerate the response of Uganda to children living with AIDS. We need to ensure that staff development remains an important aspect of improving quality care at the Baylor - Uganda as more patients seek our services. The Baylor College of Medicine Children's Foundation - Uganda, along with the department of Paediatrics and Child Health, will set up strategies to ensure that the clinics remain financially and administratively sound as we work towards our objectives.

Finally, there is need to foster diverse partnership for sustainability of a comprehensive programme. To our partners, we are grateful for your continued goodwill and support. We look forward to developing even closer collaboration as we all work together towards our mission.



Artistic impression of the new Children's Centre of Excellence, currently under construction.

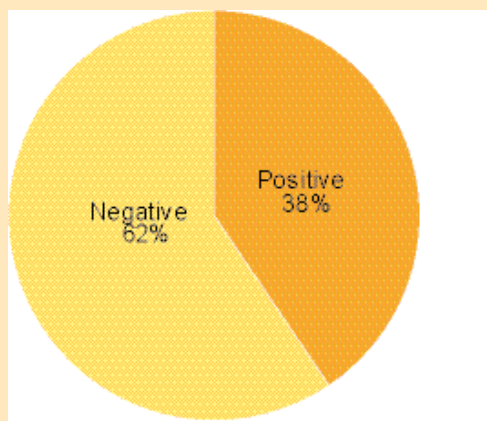


i. Counselling and testing

a) Counselling and testing children (below 18 years)

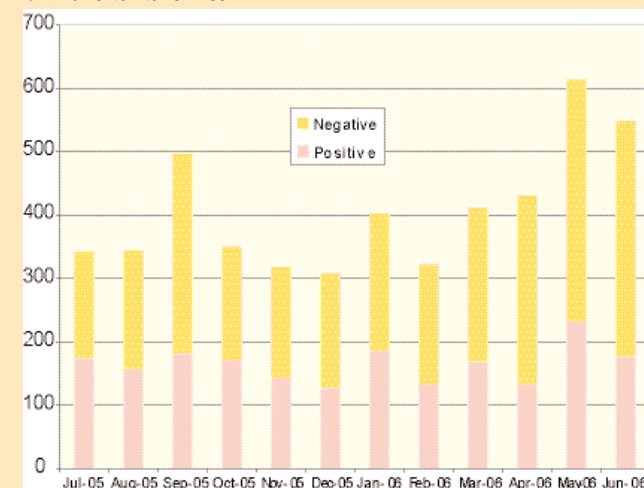
Between July 2005 and June 2006, a total of 5,373 children were counselled for HIV testing. Of these, 3,672 were counselled at Mulago Hospital PIDC Ward 15, while the rest were at satellite clinics (528 at Kawempe, 425 at Naguru, 461 at Mulago post-natal clinic and 135 at TASO Kanyanya).

Percentage distribution of total number of Children tested



A total of 1,983 (38%) tested HIV positive. In order to increase access to HIV testing services, Baylor - Uganda incorporated it into the Home Health Care Package where all members of a visited household are offered an opportunity to test and know their HIV status. The programme started in May 2006 and by 30th June 152 people had been tested, of which 97 were children 0-18 years. All the 11 people who tested HIV positive in the community were adults above 18 years of age and all were linked to care.

Monthly distribution of children counselled and tested at PIDC Ward 15 and satellite clinics



The months September, January and May depict the opening of three new satellite clinics

b) Counselling and testing adults (above 18 years)

HIV testing of adults by Baylor - Uganda clinics started in August 2005 with collaboration from the Infectious Diseases Institute (IDI), Mulago-Mbarara Teaching Hospitals' Joint AIDS Program (MJAP), AIDS Information Centre (AIC) and Protecting Families Against HIV/AIDS (PREFA).

The main target groups were caretakers of children already in care, geared towards providing a convenient service for families, especially mothers. It was envisaged this would reduce the number of visits mothers make to health facilities for such services.

A total of 3,474 individuals were tested, with 915 (26%) testing HIV-positive.

The majority of adults tested were in Kawempe and Naguru where family-based model of care is being offered.

ii. Basic health care and support

a) Numbers served - general

Baylor - Uganda served 4,741 children during the year at Baylor - Uganda clinics, either as HIV infected or exposed. Of these, 3,342 (75%) were HIV positive. The HIV exposed are children aged 0-18 months who were born to HIV positive mothers, tested HIV negative but are still breastfeeding. They are kept in care and only discharged on testing HIV negative six weeks after cessation of breastfeeding.

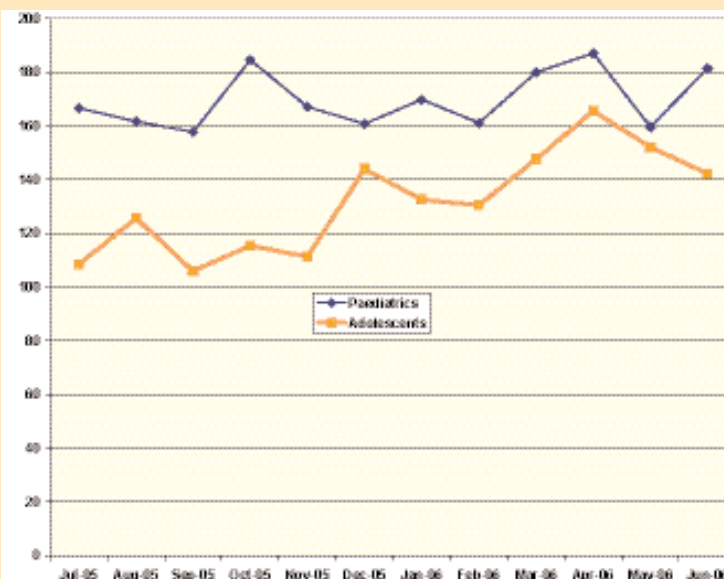
Patients served at Baylor - Uganda clinics by type of service

Site	HIV +		Total HIV+	HIV - Exposed	Total in HIV Care	HIV -	Total Served
	HAART	Non-HAART					
PIDC Ward 15	1,440	1,818	3,258	730	3,988	1,943	5,931
Kawempe	28	68	94	79	173	63	236
Naguru	8	59	67	165	232	118	350
Post Natal	19	51	70	217	287	1	288
Kanyanya	6	47	53	8	61	78	139
Total	1,499	2,043	3,542	1,199	4,741	2,203	6,944

An average of 2,073 patients were seen each month at Baylor - Uganda clinics. 53% of them were to get their HAART drugs.

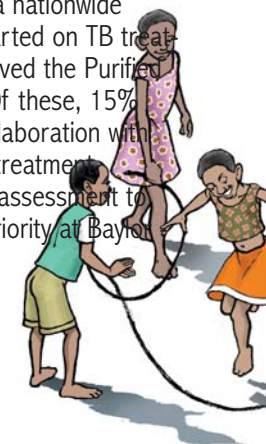
Average daily attendance for paediatrics and adolescent clinic days at the PIDC centre of Excellence is 168 and 120 respectively.

Daily Clinic Attendance at Mulago - PIDC Ward 15



b) Management of opportunistic infections

Ongoing assessment, diagnosis and treatment of Opportunistic Infections (OIs) in HIV-infected children has continued to be top priority at Baylor - Uganda clinics. During the year, TB management at PIDC Mulago increased considerably compared with the previous year which saw a nationwide scarcity of TB drugs. A total of 414 patients had been started on TB treatment by 30th June 2006. In addition, 1,114 children received the Purified Protein Derivative (PPD) test for tuberculosis screening. Of these, 15% were reactive, implying they had TB infection. Through collaboration with Paediatric AIDS Canada, 28 children received anti-cancer treatment. Provision of Cotrimoxazole prophylaxis and its adherence assessment to HIV positive and HIV exposed patients still remain a top priority at Baylor - Uganda clinics.



c) Basic care package

The basic health care package consists of cotrimoxazole, bed nets, safe water vessels and a disinfectant. In line with the Ministry of Health policy, cotrimoxazole is distributed to all HIV infected and HIV exposed children and adults attending PIDC Centre of Excellence and the satellite clinics. To date, 2,589 children and families have received at least two bed nets each. Distribution of safe water vessels started in October 2005 and to date, 1,597 families have benefited.

66 children
are being
started on
ART monthly

iii. ART drugs

Initially, ART services were supported by Pediatrics AIDS Canada (PAC), Joint Clinical Research Centre (JCRC) and Ministry of Health (MoH), serving up to 340 children. The service was rolled-out in January 2005 through the President's Emergency Plan for AIDS Relief (PEPFAR) grant to Baylor College of Medicine. By the end of June 06, a total of 1,537 patients had received drugs from Baylor - Uganda clinics. Of these 792 (52%) were started during this reporting period, and an average of 66 children are being started on ART monthly.

Child development and play therapy

Background

The Child Development and Play Therapy Centre (CDPTC) started on 12th December 2005. It was created to offer support for the emotional, intellectual and physical well-being of the children attending Mulago Hospital PIDC clinics. Lessons focus on the development of listening, speaking, reading and writing skills. Other non-academic lessons are provided as well. These address topics such as music, art, hygiene and physical fitness. CDPTC activities are focused on young children, especially those in nursery class

through P6.

Additionally, childhood growth and development is supported through activities such as exploration with building blocks and puzzles, story telling and dramatic play, discussion of family life and relationships, and lessons for healthy living.

Current activities

The following materials are available to the children to support their learning and well-being:

- Exercise books for each child from P3 to P6
- Black slates, chalk and dusters for children in nursery class, P1 and P2
- Magnetic letters and numbers for creating words, learning letters, numbers and simple math problems
- Colouring book pages and crayons for drawing pictures
- Building blocks, puzzles, a tea set, story books, blowing bubbles, coloured plastic balls for free exploration activities with all children. In addition story books also keep the older children busy.

Achievements

The Child Development and Play Therapy Centre has been a positive influence on the behaviour of children attending PIDC clinics. The children no longer run in and out of the clinic; they now sit quietly on a mat waiting for lessons and other activities to begin. Parents and guardians who bring children to the PIDC clinics support this new service by sitting and listening to the children sing, recite, respond to questions and write letters, words, sentences and numbers.



Teacher Jane Beyeza conducts a lesson with Baylor College of Medicine Childrens Foundation - Uganda children

Future plans and recommendations

The following plans and recommendations address issues of growth and continued development of CDPTC activities:

- A curriculum of learning activities will be finalised to provide a structured outline of lessons and activities used each week with the children. A second teacher or volunteer teacher assistant shall be added so that lessons can be tailored for Nursery Class to P2 and P3-P6. An additional teacher will also support general management of the children as the number of children often exceeds 50, especially in the early morning hours.
- Future provision of a separate room or CDPTC area in the clinic will allow for an increase in the number of children participating in programme activities and also provide for a more comfortable environment for the children as they are currently crowded in the designated area of the PIDC waiting room.
- Additionally, designation of an annual budget to support CDPTC activities will allow for the replacement of supplies and the purchase of new teaching materials.



Pharmacy

Background

Providing care and treatment to HIV positive children can be seen by some health providers as a challenging proposition. Issues of paediatric drug formulations and dosing can leave some health providers feeling ill-prepared to serve this special population of patients. Since the initiation of paediatric HIV care services in Mulago Hospital's Ward 15 in July 2003, the capacity to consistently and effectively provide pharmaceutical treatment interventions to our paediatric patients has been continually growing.

Progress

In the advent of increased access to ARV treatment, the Baylor - Uganda pharmacy team revised their treatment delivery practices to meet the growing demands. Below are some of the innovative service developments and successes realized over this past year.

- **Expansion of drug dispensing capacity** - in order to reduce patient waiting time and address backlog related to the continually growing demands for HIV care and treatment, a second pharmacy dispensing outlet was created at the Mulago Hospital PIDC Ward 15. This outlet was an ordinary clinic window turned into a dispensing outlet. Minor renovations were made to this area, including a small table top work area and cubical with a lockable door. One dispensing outlet/window is dedicated to dispensing ARVs while OI medications are dispensed out of the second window. This additional dispensing window allows for more efficiency in drug dispensing.

- **Heavy duty pill cutters** - Acquisition of three industrial pill cutters has greatly enhanced the efficiency of pill cutting and medication packaging activities within the Baylor - Uganda pharmacy. These pill cutters have heavy duty pill cutting blades and specially designed trays that can

hold up to 10 pills at a time. This allows for the splitting/cutting of a larger number of pills at once. These pill cutters are used at the main PIDC clinic at Mulago Hospital as well as other Baylor - Uganda satellite clinics in Kawempe, Naguru and Kanyanya - TASO.



Pill cutter used in Baylor - Uganda pharmacy to support accurate dosing in children

- **Secure, air-conditioned drug store** - the majority of the Baylor - Uganda drug stock, including ARVs, are stored in a secure, air conditioned storage area which was renovated using PEPFAR funding. A cold chain is maintained in the store for medications requiring refrigeration. Additionally, a temperature log is kept in order to continually monitor temperatures of the drug store room and refrigerator. These temperatures are checked and recorded twice daily - morning and evening.

- **Inventory monitoring and management** - the implementation of a strict, manual inventory management system allows for full inventory accountability. Real-time recording of medications in and medications out is performed, while inventory audits and reconciliation is conducted monthly.

This inventory management system also supports the forecasting and ordering of drugs, ensuring that there have been no drug stock-outs at the Baylor - Uganda clinics.

- **Increasing numbers of children started on HAART** - the Baylor - Uganda pharmacy team has continually met the challenges presented by a growing demand for paediatric HIV care service. By the end of June 2006, the Baylor - Uganda pharmacy at PIDC was dispensing ARV treatment to 1,440 patients, while prophylactic and other supportive medications are continually dispensed for the more than 3,258 patients in active follow-up.

- **Satellite pharmacies** - during Fiscal Year 2005 the Baylor College of medicine Children's Foundation - Uganda expanded its services to Three Kampala City Council (KCC) clinics, namely Kawempe, Naguru and Kanyanya - TASO clinic. Baylor - Uganda dispensers work side-by-side with KCC dispensers to build capacity in dispensing paediatric HIV medications, including ARVs. Paediatric HIV pharmacy and dispensing services are now fully operational at these three satellite clinics.

- **Medication dosing and adherence support** - Many caretakers of Baylor College of medicine Children's Foundation - Uganda patients, particularly the elderly, are unable to ensure that the children take the right amounts of ARVs at the right times. Low literacy and poor eyesight of elderly caretakers are some of the factors leading to poor dosing and adherence. In an effort to address this challenge, the Baylor - Uganda pharmacy team has set up a demonstration

area for working with caretakers in the different clinics. A Baylor - Uganda dispenser sits with a caretaker and provides one-on-one demonstration of proper ARV syrup dosing/measurement. The caretaker is then asked to provide a return demonstration to ensure he/she has understood the dispensing techniques.

Baylor - Uganda dispensers work side-by-side with KCC dispensers to build capacity in dispensing paediatric HIV medications, including ARVs



An assortment of ARV medications in Baylor - Uganda drug store



Challenges

- The rapid increase in patient numbers and the resultant heavy workload puts stress on the limited work space available. The Baylor - Uganda pharmacy at PIDC is a small room accommodating as many as four staff members cutting, packaging, dispensing, keeping records and monitoring pharmacy operations. Operating in this squeezed space could compromise the quality and efficiency of work.

- The current pharmacy at PIDC, Mulago space does not have a sink. As a result staff frequently move out of the pharmacy to wash their hands since hand-washing is one of the crucial procedures in maintaining hygiene and good pharmacy practice. Unfortunately such up and down movements compromise efficiency.

- The space for Baylor - Uganda drug storage at the PIDC, Mulago is no longer adequate. Thus Baylor - Uganda can stock only a limited quantity of drugs at a time. This leads to frequent drug deliveries from drug suppliers, which is inefficient and somewhat disruptive to daily pharmacy operations.

- Pharmacy stock management information system - although the manual stock management system currently in use at Baylor - Uganda clinics is working well, movement to an electronic stock management information system (MIS) would increase efficiency and ease regular reporting and forecasting of activities. Such activities include monthly drug usage reporting, medication expiration date monitoring, and drug forecasting and ordering.

Way forward

- Space - an additional small, secure storage area has been built at Mulago, PIDC to immediately address drug storage issues. A larger pharmacy with a sink and adequate drug storage facilities will be included in the Center of Excellence building.

- Automated pharmacy stock management information system - it is anticipated that an automated Baylor - Uganda pharmacy management

system will be developed and implemented during FY06. The Baylor - Uganda data management team will liaise with Medical Access as well as CDC-Uganda to adapt their automated pharmacy information management systems to meet the needs of our pharmacies.



Clients in a doctors consultation room at a Baylor Uganda Kawempe Satellite

Home Health Programme

Background

In anticipation of Baylor - Uganda antiretroviral (ARV) treatment scale-up, the need to increase home visit capacity became apparent. In February 2005, Baylor - Uganda held a partners' meeting with representatives from the Centers for Disease Control and Prevention (CDC) Uganda office, Infectious Disease Institute (IDI) and Child Advocacy International (CAI) to launch the Home Health Programme development activities. At that time, monthly home follow-up of 150 Baylor - Uganda patients was being provided by CAI.

With increased access to antiretroviral therapy, the need for in-home palliative care declined, while there was an increased need for adherence support, follow-up and tracking of patients, home-based HIV counselling and testing (HBHCT), and HIV basic preventive care. It was also agreed that since PIDC Mulago is a national referral centre with a facility-based model, the home-based services would augment, rather than replace, care provided at the clinic. Baylor - Uganda is indebted to CAI that had set the stage for large-scale acceptance of home visits with its exemplary record and reputation with clients' families.

Over the last year, the Baylor - Uganda Home Health Programme has concentrated on follow-up and tracking of patients, adherence support and HIV basic preventive care support/family health promotion. Standard Operating Procedures (SOPs) were developed to guide the Home Health Workers (HHWs). Also developed were Home Health Visit (HHV) programme tools that support the SOPs. Special recognition must be made of Dr. Jeannie Y. Chang Pitter, Baylor - Uganda Clinical Coordinator, who spearheaded most of these developments. Baylor - Uganda tools were developed in consultation with and through referencing from other providers like The AIDS Support Organization (TASO) and CDC-Uganda.

Other developments over the past year include the procurement of motorcycles and other programme equipment, construction of a motorcycle shed, development of a computerised patient tracking system and a data-

base to support and analyze data obtained in the field. The tracking system, in the final stages of refinement, is expected to direct timely patient follow-up.



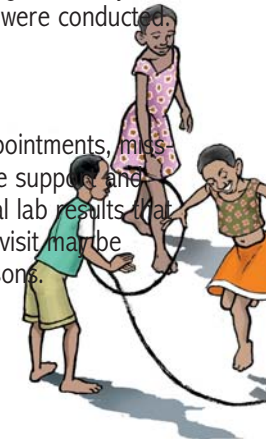
A home health worker carrying out a pill count at a clients home

Routine home visits

Baylor - Uganda's target for routine home health visits (HHVs) is to visit every patient on ART at least twice in a quarter for Adherence Support and an Unannounced Pill Count (UPC), Home-Based Family Health Promotion in HIV Basic Preventive Care, and a Household Census. During financial year 2005, (1st July, 2005 - 30th June 2006) 450 home visits were conducted.

Triggered home visits

The need for a home visit may be triggered by missed appointments, missing patients, need for urgent ARV drug delivery, adherence support and other psycho-social difficulties, and the reporting of critical lab results that need immediate attention. Requests for a triggered home visit may be made by in-clinic staff members for any of the above reasons.



Patient tracking

The Baylor - Uganda Home Health Team attempts to track patients who have missed appointments and missing patients (patients who have not appeared in the clinic for more than two months) by calling all those who have a phone. More than 2,390 phone calls for tracking purposes were made this year. A home visit is also done for patients on HAART who live within the catchment area (less than 30 km) who have missed their visit or have become missing and cannot be reached by phone.

Challenges

The challenges faced in providing home visits to Baylor - Uganda patients on ARV therapy include:

- Transportation - Baylor - Uganda currently has only one vehicle dedicated to supporting home health activities.
- Locating Patient Homes - due to inadequate information about household locations and unclear addresses, tracking patients who get lost to follow-up becomes a nightmare and a time consuming exercise.
- Lack of reliable phone contacts - only 53.2% (419 out of 788) of patients who were called for missed appointments could ultimately be reached on the number provided.
- Inadequate staffing, high Patient/Home Health Worker Ratio - due to the high patient to HHW ratio, the HHW can trace (follow-up) only a limited number of patients.

Stigma and non disclosure - a significant number of our caretakers do not disclose to their family members and close friends for fear of stigma. Such clients are likely to decline being escorted home because this may reveal their situation to family members.

Frequent shifting of home residence - orphans and vulnerable children often end up migrating from one home to another, making it difficult to trace them. 46% of PIDC patients are single orphaned while 15% are double orphaned.

- Difficulty in assessing adherence to syrups - to measure adherence where the drug is in syrup form, one just makes an intelligent guess, which may not be as accurate as counting pills.

Future plans

The Home Health Programme looks forward to implementing the following activities in the coming year:

- Transportation - three motorcycles will be procured to enhance HHP activities.
- Patient tracking - further emphasis will be put on home visiting to ensure that patients on ARV drugs are visited at least twice in a quarter.
- Personnel - additional home health workers will be hired and community members will be integrated to allow for the follow-up of more patients and implementation of Home-Based HIV Counselling and Testing (HBHCT).
- Data management - data management will be strengthened through the continued enhancement of the Baylor College of Medicine Children's Foundation - Uganda Home Health Programme patient tracking, reporting, and data collection systems.



Adolescent Programme

The Baylor College of medicine Children's Foundation - Uganda Adolescent Programme for HIV positive children aged 10-19 years has continued to grow over the past three years. Currently, more than 400 clients attend the Adolescent Clinic, which runs at Mulago clinic on Tuesdays. All patients attending this specialised clinic receive standard of care in HIV clinical monitoring and are also able to participate in a monthly adolescent peer support group. The main criterion for participation in the peer support group is disclosure or knowledge of one's HIV status. All adolescent programmes are supervised by Dr. Sabrina Bakera Kitaka.

Currently there are more than 250 adolescents who benefit from the Baylor - Uganda Adolescent Peer Support Group. All adolescents needing anti-retroviral therapy have been able to access it through the Baylor - Uganda, clinics.

Adolescent Peer Support Group

The adolescent peer support group (designated the "Mulago Teen Club" by the adolescents themselves) provides psychosocial support to Baylor - Uganda clients between 10 and 19 years of age who know their HIV-positive status. One goal of the support group is to provide adolescents with a forum to share ideas, express feelings and learn life skills.

During the initial stages of peer support group programme development, the children were divided into three groups based on age: 10-12 years (Kids Club), 13-15 years (Sharp Club) and 16-19 years (Bright Group). At each monthly support group meeting, the adolescents divide themselves into their groups to discuss the month's topic within each age group. At the end of each support group meeting, the adolescents re-assemble and report on discussion highlights before breaking for music, dance and refreshments.

The number of adolescents attending Peer Support Group/Teen Club meetings on a monthly basis has stabilised at approximately 160. During Christmas holiday celebrations, there were as many as 186 adolescents.

Adherence promotion and monitoring: All peer-support group meetings over the past four months have been geared towards addressing

this issue. A peer support group for parents and guardians of adolescents has also been formed especially to address treatment adherence issues in this unique population of patients.

The January 2006 peer support group meeting was honoured by His Excellency the Governor of Manitoba, Honourable Peter Liba and his wife as well as accompanying delegates. The Mulago Teen Club Drama Club performing to their best. In an effort to diversify the peer group

One goal of the support group is to provide adolescents with a forum to share ideas, express feelings and learn life skills



His Excellency the Governor of Manitoba, Honourable Peter Liba paid a visit to Mulago Teens Club

meetings and make it more interesting for adolescents, a sports gala sponsored in part by Motor Care Uganda Limited was organised successfully in February 2006.



Challenges

● Adherence is a major challenge in this group, with attendant concerns of treatment failure. Preliminary results from an adolescent study have shown that up to 20% (18 out of 90) adolescents experience virological failure by 12 months of treatment. The study found that some of the reasons for lack of adherence included:

- Drug-fatigue
- Peer pressure
- Influence from spiritual leaders
- Inadequate adult supervision
- Adherence difficulties for children in boarding schools

● Sex and sexuality - major emphasis has also been placed on issues of sex and sexuality during this last quarter, having realised the increasing number of adolescents engaging in sexual activities as ARV medication improves their health. Three (3) pregnancies have been identified during the past four months, which presents three major dilemmas:

● Girls who conceive while taking medications that are not recommended for use during pregnancy, such as Efavirenz, could expose the foetus to risks.

● There is also a risk of transmitting HIV to the foetus.

● Placement of the young mothers-to-be in an appropriate follow-up clinic becomes a challenge - should they remain in the adolescent clinic or be shifted to the adult clinic?

● Adolescent transitioning - When adolescents outgrow the clinic, that is, when they exceed 18 years of age, ideally they should belong to an adult clinic. However, some adolescents have continued to receive care at - Mulago clinic due to the difficulties of transitioning them to an adult

Future plans

● A one-week teen club day camp is planned for September 2006

● Sharing lessons learnt and best practices with other centres implementing adolescent HIV care

● Developing peer group leaders to promote treatment adherence and adolescent HIV care through participation in international meetings

● Initiating a plan to transition adolescents into the family clinic once they exceed 18 years.



Mulago Teens Clubs members on their camp day at Kololo.



Community-Based Voluntary Counselling and Testing (CBVCT)

Background

The primary goal of the Community-Based Volunteer Counselling and Testing (CBVCT) activities is to enable household members of children attending Baylor College of medicine Children's Foundation - Uganda clinics to get tested for HIV in their own communities so that they may know their status. As many families and guardians are unable to bring all their household members for testing, this initiative takes vital service to people where they stay.

The Baylor-Uganda initiated CBVCT activities in September 2005 in response to a request from the HIV-positive women's group, Bead For Life. The women of Bead For Life asked Baylor-U to come to their community and test their children. On 22nd and 29th September 2005, 66 children of Bead for Life mothers were tested in their own community. This marked the beginning of CBVCT. Those children who were found positive were referred to HIV clinics for ongoing care, while mothers whose children were negative received risk-reduction counselling.

Current activities

Following these pilot CBVCT activities with Bead For Life, the need and community desire for family-focused HIV testing services became apparent. Baylor College of medicine Children's Foundation - Uganda organised additional CBVCT days in response to direct requests from local organisations. On 14th January, 2006 a CBVCT open day was held at Kawempe Health Center. One of the caregivers of a child receiving care at Baylor - Uganda Kawempe Satellite Clinic mobilised 21 families to come for testing that day. Additionally, CBVCT days were held on 3rd February and 1st April 2006 in response to requests from Kawempe Police Post and Feed the Children –

UGANDA respectively. A total of 110 children and adults were tested for HIV on those two days, with 83 of the 110 tested being children. Children who were found positive were referred to the Mulago PIDC or one of its satellite clinics. Adults who tested HIV positive were referred to the Mulago Hospital Immuno-Suppressive syndrome (ISS) clinic or another clinic of their preference.



Family members of Police Officers at Kawempe Police station attend a Community Based HIV Counseling and Testing Day at a KCC Clinic.

Future plans

Similar CBVCT outreach programmes are to be integrated into the growing spectrum of Baylor College of medicine Children's Foundation - Uganda services and activities. A formal CBVCT timetable will be drafted so that programmes may run throughout the year. The energy of Baylor - Uganda patient caretakers will be leveraged to mobilise other families in the communities to come for family/household HIV testing.



Health Profession Training and Capacity Building

Background

Until a few years ago, expertise in paediatric HIV care and treatment was scarce in Uganda. Health professionals and families alike believed there were few options available for children infected with HIV. Many of these children were left to lead sickly and hopeless, short lives due to this unnecessary knowledge gap.

This situation has changed, however, through the efforts of institutions such as the Mulago Hospital/Makerere University Department of Paediatrics and Child Health, Centers for Disease Control and Prevention (CDC) -Uganda, and Baylor College of Medicine, Baylor International Paediatric AIDS Initiative (BIPAI). Through a CDC University Technical Assistance Programme-Global AIDS Programme (UTAP-GAP) grant to Baylor College of Medicine, Baylor and Mulago Hospital/Makerere University have worked together since 2003 to develop a paediatric-specific HIV care and treatment training programme.

The first five-day paediatric-specific, HIV/AIDS training workshop was delivered to 25 Mulago Hospital/Makerere University Department of Paediatrics and Child Health faculty and staff in November 2003, with the training materials primarily delivered by expatriate BIPAI staff. Since then, the five-day BCMCF - Uganda/Baylor training workshop has been continually updated and revised to address issues most relevant to the Ugandan setting. Today, most of the training sessions are facilitated by local clinicians either from the BCMCF - Uganda or the Mulago/Makerere Department of



Participants (Baylor - Uganda staff) holding a group discussion at a Good Clinical Practice Training workshop, at Hotel Africana.

Paediatrics and Child Health.

In addition, other paediatric training workshops have been developed to meet the growing needs and interest of health professionals in delivery of paediatric HIV/AIDS care and treatment. These workshops include a paediatric HIV care and counselling workshop, as well as a joint paediatric and adult HIV workshop to assist in developing the skills of clinicians who will deliver HIV care in a family health setting, i.e. seeing both children and adults together.

Through the Baylor UTAP grant, over 373 health professionals have benefited from this specialised training programme. The trainings are tailored to cater for an interdisciplinary group of health professionals such as nurses, doctors, counsellors, dispensers and laboratory technologists in order to foster the interdisciplinary team approach to providing paediatric HIV/AIDS care.

Other ongoing BCMCF - Uganda in-service/health professional training

In addition to formal training workshops, there are opportunities for Baylor - Uganda staff to receive in-service training weekly. Below is a schedule of some of the in-service training opportunities available through the BCMCF - Uganda and its partnership with the IDI.

Weekly pre-clinic continuing medical education opportunities

- Monday: HIV/AIDS Journal Club – IDI
- Tuesday: Paediatric Radiology Consultations/Training – BCMCF - Uganda
- Wednesday: Paediatric HIV In-service Lectures - BCMCF - Uganda
- Thursday: Paediatric HIV Case Conference - BCMCF - Uganda
- Friday: Adult and Paediatric HIV Case Conference - IDI

The weekly in-service trainings are open to all Mulago Hospital staff and students. In-service training attendees include an interdisciplinary group of health professionals, including medical officers and doctors, nurses, counsellors, and laboratory technicians. The Wednesday Paediatric HIV In-service Lectures hosts an average of 40-45 health professionals each week.

BCMCF - Uganda Clinical Attachments

As a way of supporting knowledge and skills introduced through the BCMCF - Uganda/Baylor-sponsored training workshops, PIDC - Mulago hosts health professionals from various agencies and institutions so that they may gain practical experience in delivering paediatric HIV care and treatment services. Health professionals come to PIDC for clinical attachments for periods ranging from two days to two months. These health professionals have come from all regions of Uganda and have included doctors, clinical officers, counsellors, nurses, dispensers, and laboratory technologists. To date, 80 health professionals have benefited from the attachments.

Information, education and communication (IEC) materials development:

The availability of patient education materials remains a significant gap in providing quality care to paediatric HIV patients and their families. To address this shortfall, such materials were developed through funding from the Baylor UTAP-GAP grant. Adherence and general health education/counselling support materials were developed through a local educational materials development company in Kampala. Key BCMCF - Uganda clinical personnel participated in the development of these materials, which resulted in tools such as a set of 12 HIV and ARV patient education cards. Key messages that were to be used to support the visual story presented on the front of the cards were developed by the BCMCF - Uganda team working on this project. All BCMCF - Uganda physicians, counsellors and dispensers have received a set of these cards so that they may use them to support their individual care and treatment counselling efforts. Other materials including nutrition, hygiene, bed net use, and ARV adherence posters were created. A patient education video to be played in the BCMCF - Uganda waiting area is now in development through support of UTAP-GAP funding.

This video will highlight hygiene, medication adherence, clinic procedures/processes, etc. It is anticipated that video production will be complete in the near future.

The way forward

Regional Paediatric HIV Experts Training/Development

In support of continuing paediatric ARV treatment scale-up in Uganda, the BCMCF - Uganda/Baylor collaboration has joined with the Uganda Ministry of Health and two other local organisations—Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) and the African Network for the Care of Children with AIDS (ANECOA) — to develop paediatric HIV care and treatment expertise throughout Uganda. This National Paediatric HIV Experts Training collaboration will support “Advanced Paediatric HIV Care and Treatment” training programmes to promote the development of individuals identified as paediatric HIV treatment experts in the various regions of Uganda. The first of these regional experts’ trainings was conducted 6-10 February, 2006. Two of the regional experts who participated in that training assisted in delivering training in their home region the following month. Health professionals from the Kabale, Mbale, Mbarara, Masaka, and Hoima districts participated in this first regional experts training. The individuals identified to serve as regional experts will be supported with advanced paediatric-specific knowledge and care/treatment skills through practical attachments and support supervision. These workshops and follow-up experiences will highlight practical experience and development of clinical mentorship and training skills so that these individuals may return to their regions and serve as paediatric HIV care and treatment experts.

Support Supervision

Provision of support supervision to health professionals after they return to their home institutions is seen as one of the key developments of the BCMCF - Uganda training programme in FY06. The support supervision will require use of a vehicle and availability of clinicians such as one physician, nurse, counsellor and driver. Such an activity will support the practical implementation of skills learned during the didactic training, while supporting the evaluation of training impact after someone returns to their home institution. Support supervision will also support capacity building in the various regional settings.



Human resources

The BCMCF - Uganda team

For an organisation to excel, it needs personnel with expertise, experience, vision and zeal for achieving a common goal through teamwork. To the individuals in the Baylor College of medicine Children's Foundation - Uganda team, their work is more than just a job; they are driven by the desire and ambition to fight the HIV/AIDS epidemic through providing paediatric HIV/AIDS care and treatment services which will enhance the health and quality of life of children and families in Uganda and, potentially, around the world. Special thanks go to Mulago Hospital and to Baylor - Uganda partner organisations, especially BIPAI and the Infectious Diseases Institute for the technical, moral and financial support they have provided, which has enabled the Baylor - Uganda to increase its staff numbers in response to the rapidly growing demand for paediatric HIV care and treatment services. The following people comprise the Baylor College of medicine Children's Foundation - Uganda management team, through which these goals are being achieved.

Leadership

**Head of Department
Paediatrics and Child
Health,
Mulago Hospital/Makerere
University**

Philippa Musoke

Dr Musoke led the expansion of the Paediatric HIV Clinic (PIDC) in collaboration with the Infectious Diseases Institute, CDC Uganda, Baylor College of Medicine, University of Wisconsin, Feed the Children and other partner organ-



izations. As Head of Department, she has overall leadership for the clinical services offered in the hospital including PIDC. Her area of research has included Prevention of Mother-to-Child HIV Transmission (PMTCT) and anti-retroviral therapy for infected children in resource-limited settings. The expansion of Baylor - Uganda in collaboration with multiple partners is consistent with the departmental vision to become a centre of excellence in service delivery, training and research for child health in Uganda and beyond. Through her leadership in the paediatrics department, Baylor - Uganda has been able to enhance the care of HIV-infected and affected children through clinical services, training of health workers from all over the country and relevant research.

Baylor - Uganda Executive Director:

Dr Addy Kekitiinwa
Rukyalekere, MMed
Paediatrics and Child Health
(MUK)



Dr Kekitiinwa is an associate Professor of clinical Paediatrics at Baylor College of Medicine, a senior consultant paediatrician at Mulago National Referral Hospital. She has served at this capacity since 2002. Prior to that she served as Consultant Paediatrician offering clinical leadership and training at Mulago Hospital. Dr.

Kekitiinwa is a committed, self-motivated, enthusiastic, hard-working paediatrician with leadership skills that has transformed PIDC from just one of those Mulago outpatient clinics to a paediatric centre of excellence. She is a person of unquestionable integrity, a high level of ethics and sound interpersonal skills.

As a senior consultant she successfully integrated paediatric meningitis surveillance, a programme under Ministry of health and WHO, into routine paediatric care at Mulago and two other district hospitals, making Uganda the leader in bacterial meningitis surveillance. For four years she was the

deputy coordinator of the Makerere University paediatric post graduate programme. Dr. Kekitiinwa holds a masters degree in Paediatrics and Child Health of Makerere University and has more than 18 years of teaching experience.

Project Manager/Training Coordinator:

Ms Susan A. Kelly, MPH

Ms. Kelly is the Project Manager for Baylor College of Medicine, Baylor International Paediatric AIDS Initiative (BIPAI) activities in Uganda. She has worked in Uganda since August 2003 and has played a key role in establishing Baylor's collaboration with Mulago Hospital/ Makerere University. In addition to serving as the Baylor Project Manager, Ms Kelly is the Baylor Training Coordinator.



Through a University Technical Assistance Programme (UTAP) grant to Baylor College of Medicine from CDC, she has worked side-by-side with Mulago Hospital/Makerere University Department of Paediatrics and Child Health faculty to develop a paediatric-specific HIV/AIDS care and treatment training programme, which trains more than 250 health professionals each year.

Ms. Kelly holds a Master of Public Health (MPH) degree in International Public Health from the George Washington University in Washington, D.C., USA, and has more than eight years of experience working in HIV therapeutics research with the AIDS Clinical Trials Group (ACTG).

Clinic Manager: **Mr Methuselah Kahungu**

Mr Kahungu comes to Mulago - PIDC through its collaboration with the Infectious Diseases Institute Ltd (IDI) and has a strong background in Comprehensive Nursing and Health Services Management. He manages the daily operations of the clinic. He plays a key role in personnel management at the level of coordination and oversight of daily clinic staffing, management of medical supplies use and procurement, and providing oversight and management of daily operations. He also coordinates health professional attachment and volunteer programmes at the Mulago PIDC.

Mr. Kahungu has four years of experience in management of decentralised public health services and two and a half years experience working with non-governmental organisations (NGOs), including IDI and ADRA Uganda.

Clinical Services Coordinator: **Dr Jeannie Chang Pitter**

Dr. Pitter is an Instructor of Paediatrics at the Baylor College of Medicine, Division of Retrovirology. She works in Uganda through programme activities of the Baylor International Pediatric AIDS Initiative (BIPAI). Dr Pitter completed medical school training at Stanford University, and her paediatric residency at the University of California, San Francisco.

Dr. Pitter has been working at the Mulago PIDC for two years as Clinical Coordinator and has been instrumental in developing Paediatric specific clinical forms, the home health programme, and other quality of care initiatives.

Head of Finance & Administration: **Ms. Helen Awidi**

Ms. Awidi is a Chartered Certified Accountant (AACA) with 10 years working experience in Financial Management with an international NGO. Five years of her work experience has been in the key position of Finance and Administration Manager with Plan Uganda. Ms. Awidi has expertise in budgeting/budget management, accounting, procurement, asset management and staff supervision.



Head of Laboratory Services:

Mr. Benedict Mukwaya

Mr. Mukwaya comes to the Mulago PIDC through its collaboration with IDI. He provides oversight to the laboratories at the main PIDC its four satellite clinics. Mr. Mukwaya is the primary PIDC liaison with the Makerere University/Johns Hopkins University (MUJHU) Core Laboratory and oversees the Mulago PIDC laboratory quality assurance programme. He supervises a team of six laboratory technologists and technicians.

Mr Mukwaya holds a Bachelors Degree in Biomedical and Laboratory Technology from Makerere University and recently completed further training in Good Clinical and Laboratory Practices (GCLP) in South Africa.

Head of Pharmacy:

Mrs. Jacque Mpanga Takubwa

Mrs. Mpanga is a registered Pharmacist with a bachelor's degree in pharmacy from Makerere University and a Post-Graduate Diploma in Project Planning from the Uganda Management Institute. She has 11 year's experience as a Pharmacist, particularly in the HIV/AIDS field, and was one of the first Pharmacists in Uganda to dispense antiretroviral medications.

Mrs. Mpanga leads a team of five pharmacy technicians and one nurse. Together, they serve between 150 and 200 patients per clinic day; the majority of these patients are on HAART. In addition the pharmacy procures, forecasts, stores, budgets and accounts for all the drugs that patients require; both ARV's and drugs for opportunistic infections.

Head of Data Management:

Mr. Albert Maganda

Mr. Maganda is the Head of the Data Management Division of the Baylor College of medicine Children's Foundation - Uganda and is the Lead Data Manager for Baylor International Paediatric AIDS Initiative (BIPAI) activities in Uganda. He has been the main brain behind the transformation of

Mulago PIDC's manual record keeping and registry systems into a fully functional electronic patient tracking and health management information system (HMIS). He has also been leading Baylor College of Medicine Children's Foundation - Uganda Monitoring and Evaluation (M&E) activities.

Before joining Baylor College of Medicine Children's Foundation - Uganda in January 2005, Mr. Maganda worked with Makerere University – Case Western Reserve University Research Collaboration as a Data Manager/Data Analyst for TB/HIV studies for 8 years. Mr. Maganda holds a Bachelors of Statistics Degree (B.Stat) from Makerere University and he is due to graduate with a Masters in Statistics (Biostatistics) later this year. He has also attended summer courses in Biostatistics and Epidemiology at the John Hopkins University Institute of Public Health in Baltimore, MD, USA.

Coordinator Baylor - Uganda Satellite Clinic Initiatives:

Dr. Hanifa Naamala Sengendo

Dr Sengendo is a Paediatrician and the coordinator for Baylor College of Medicine Children's Foundation - Uganda satellite clinic activities, which work in partnership with other local HIV/AIDS care organisations to deliver family model HIV care and treatment to people in their communities. Dr. Sengendo holds an MBChB and Master of Medicine (MMED) in Paediatrics from Makerere University. She has over four years of experience in paediatric HIV care and treatment, specialising in malnutrition and other nutritional issues.

Dr. Sengendo is an honorary Makerere University Medical School Lecturer and has trained medical students in topics including malnutrition and infant feeding, paediatric HIV care and treatment, and reproductive health. As the Baylor College of Medicine Children's Foundation - Uganda satellite clinic coordinator, she is the primary liaison with partner organisations also supporting the satellite clinic Family HIV Care model. She is also involved in on-site support supervision, distribution of the basic care package for disease prevention, and hands-on provision of paediatric HIV care and treatment.



Family Clinic Director: Dr. Adrian Hazbun

Dr. Hazbun is one of the first members of the Baylor Pediatric AIDS Corps (PAC) sent to Africa to provide care for HIV-positive children. He comes to Baylor College of Medicine Children's Foundation - Uganda through the Baylor College of Medicine/Bristol Meyers Squibb collaboration, which supports PAC activities.

Dr. Hazbun completed a double major in Molecular Biophysics & Biochemistry and Organismal Biology for a Bachelor of Science degree at Yale University. He then taught chemistry as a Peace Corps volunteer at Minaki Secondary School in Tanzania from 1995-1997. He returned to the U.S. for further studies and earned his Degree of Medicine at Temple University School of Medicine in Philadelphia, USA. He then completed a family medicine residency at Ventura County Medical Center in Ventura, California, USA.

Dr. Hazbun arrived in January this year after working for two months in Botswana at the Baylor-Botswana Children's Clinical Centre of Excellence. Since arriving in Uganda, he has been conducting health profession trainings in topics related to the care and treatment of paediatric HIV patients, managing the Baylor College of Medicine Children's Foundation - Uganda family clinic, and providing direct clinical care to the children who attend the Mulago PIDC.

Head of Nursing

Matron Ida Rachael Mpaata

Matron Mpaata is the Mulago PIDC sister-in-charge and a Senior Nursing Officer (SNO) with more than 30 years of paediatric nursing experience. She has worked with several paediatric units within Mulago Hospital, including the Acute Care Unit, Mwanamugu Nutrition Unit, and Child Health Development Centre. She has worked in other healthcare institutions including Bugiri and Kapchorwa hospitals.

Matron Mpaata oversees all nursing activities within Baylor College of Medicine Children's Foundation - Uganda and works with the Clinic Manager to ensure smooth running of daily Mulago PIDC activities.

Staff

The Mulago Hospital Paediatric Infectious Diseases Clinic (PIDC) began in 1988 with a small but committed group of health professionals who volunteered their services once a week to support the health and well being of children living with HIV/AIDS. Through partnerships between Mulago Hospital, Baylor College of Medicine and The Infectious Disease Institute, the clinic dramatically increased its staffing numbers and now sees children five days a week. These personnel and infrastructure developments have been the main factors contributing to Mulago PIDC's transformation into a Centre of Excellence which provides quality HIV/AIDS care and treatment to children aged 0-19 years. Hiring of staff across all disciplines has been realised as indicated in the table below.

NOTE: This table includes all Mulago PIDC staff members--full time (FT), part time (PT), consultants, and others--who contribute to the achievement of Mulago PIDC's vision and mission.

Name	Title
Leadership	
Philippa Musoke	Head of Department, Paediatrics & Child Health
Addy Kekitiinwa	Baylor College of medicine Children's Foundation - Uganda Clinic Director
Methuselah Kahungu	Clinic Manager
Sue Kelly	Project Manager/Training Coordinator
Consultants	
Israel Kalyesubula	Paediatrician
Angelina Kakooza	Paediatrician
Grace Ndeezi	Paediatrician
Sabrina Bakeera-Kitaka	Paediatrician
Clinical Services	
Jeannie Chang Pitter	Paediatrician/Head of Clinical Services
Vincent Tukei	Paediatrician
Hannifa Naamala Ssengendo	Paediatrician/Satellite Clinics Coordinator
Edith Namulema	Senior Medical Officer
Maureen Sekadde	Medical Officer



Sam Nseko Mugabi	Medical Officer
Theresa Piloya	Medical Officer
Barbara Asire	Medical Officer
Carolyn Akello	Medical Officer
Justus Mwesigire	Medical Officer
Nestor Mbabazi	Medical Officer
Iga Matovu	Radiologist
Moses Galla	Clinical Officer

Nursing

Ida Mpata	In-charge Nurse
Susan Akello	Nurse
Juliet Kayongo	Nurse
Beatrice Biribawa	Nurse
Mary Acio Elong	Nurse
Mary Grace Akello	Nurse
Jane Buyonj	Nurse
Juliet Asello	Nurse
Reginah Adoo	Nurse
Margaret Kigozi Immunization	Nurse

Finance and Administration

Helen Awidi	Finance & Administration Officer
Christine Apio	Accounts Clerk
Barbara .H. Mirembe	Administration Assistant
Isaac Tumwebaze	Messenger
Jacqueline Namuli	Messenger/Tea Lady
Moses Ikapule	Driver
William Kasangaki	Driver
Charles Mugabe	Cleaner
Michael Emeru	Cleaner
Margaret Kyasanku	Cleaner

Training

Jesca Lwanga-Okumu	Admin Asst. Training
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IT Management

Albert Koma Maganda	Senior Data Manager/Statistician
Ronald Kimuli	Junior Data Manager
Josephine Maganda	Data Clerk

Patrick Etou Lumumba	Data Clerk
Geoffrey Rwebembera	Data Clerk
Keji Cissy	Data Clerk
Nankanja Rita	Data Clerk
Tom Byabakama	Records Officer
Kenneth Musononwa	Records Assistant
Sarah Nakimera	Receptionist/Records Assistant
Robinah Kiwanuka	Receptionist/Nurse

Home Health

Dennis Mwebaze	HHW Leader
Grace Manyangwa	HHW
Kato Fredrick	HHW
Harriet Ndagire	HHW
Susan Naliba	HHW
Nakiganda Agnes Ssonko	HHW
Christopher Mutahakana	HHW
Daniel Buluba	HHW
Allen Akampera	HHW

Laboratory Services

Benedict Mukwaya	Lab Technologist - in charge
Alex Ogwal	Lab Technologist
Eruaga Christopher	Lab. Technician
Sam Balikowa	Lab. Technician
Magezi Godfrey	Lab Technician
Stephen Ndibowa	Lab Technician
George Wilson Kigozi	Lab Technologist

Counselling

Cissy Ssuuna	Nurse Counselor — in charge
Fred Ssebuuma	Counselor/Home Visitor
Juliet Kyomugisha	Nurse Counselor
Esther Kangave	Nurse Counselor
Harriet Namusisi	Counselor
Elizabeth Kasule	Counselor
RoseMary Kizito	Counselor
Cissy Kamu	Counselor

Pharmacy

Jackie Mpanga
Eric Zitubundi
Isaac Esiru
Collin Byaruhanga
Judith Tikabibamu

Pharmacist
Dispenser
Dispenser
Dispenser
Dispenser

Nutrition

Mbuya Pius Pontiano
Jonath Kyarimpa

Nutrition Assistant
Nutrition Assistant

Child Development/Play Therapy

Jane Bayeza

Teacher/Play Therapist



Group photo, Mulago Teen Club members pose while at their Didis World outing, in Kansanga, Kampala, 2005



Abstracts ready for publication

1. Viral load monitoring is critical to assess early paediatric response to Highly Active Antiretroviral Therapy in a resource-limited setting: The Ugandan experience
2. Challenges to paediatric adherence to Highly Active Antiretroviral Treatment and strategies to improve adherence among a large cohort of Ugandan children
3. Rapid scale-up of paediatric HIV/AIDS care and treatment services in a public hospital setting: Success and challenges
4. Immunological and virological response to Highly Active Antiretroviral Therapy varies with age and baseline CD4 percentage: The Uganda paediatric cohort experience
5. A prospective study of HIV-infected adolescents: Monitoring growth, development and recovery while on antiretroviral therapy

Ongoing research

Children with HIV and Malaria Project (CHAMP): A prospective longitudinal study of HIV-malaria interactions

Study team:

Makerere University: Moses Kamya, Addy Kekitiinwa, Israel Kalyesubula, Anne Gasasira,

UCSF: Diane Havlir, Philip Rosenthal, Grant Dorsey, Edwin Charlebios, Huyen Cao

Study hypotheses

- HIV infection increases the risk of malaria in children.
- Malaria is associated with accelerated HIV disease progression.
- Malaria treatment has a higher failure rate in HIV-infected children compared with HIV-uninfected children.
- TMP/SMX prophylaxis is associated with an increased risk of infection with malaria parasites containing mutations conferring resistance to SP.

Study design and follow up

A total of 300 HIV positive children aged 1-10 are to be recruited, followed up for three years and compared with HIV negative children followed in Mulago Hospital Out Patient Department (OPD). All health care is provided by the study. Routine visits include monthly visits to assess parasitaemia and disease surveillance, and quarterly visits to assess HIV disease progression (CD4, viral load, measures of immune activation). Study participants attend the study clinic whenever they are unwell. During sick visits the study participants will be evaluated for malaria whenever fever is present. The malaria treatment is a combination of artesunate and amodiaquine. The response to treatment is assessed after 14 days of follow-up. Baylor College of Medicine Children's Foundation - Uganda is responsible for ARV therapy decisions and provides guidelines for management of HIV complications. Adverse events of antimalarials, ARVs, and the combination of antimalarials and ARVs is monitored.

Progress

The study began on 7th October, 2005. A total of 134 participants have been enrolled so far. All have been enrolled on TMP/SMX and more than 95% given insecticide-treated nets.

CD4 cat.	N
< 15%	43
15 -20%	30
> 20%	61



Effect of multiple micronutrient supplementation on growth, morbidity and mortality in HIV-infected children in Uganda: A randomised double blind placebo-controlled study

Study team: Dr Grace Ndeezi

Primary objectives

- To determine the effect of multiple micronutrient supplementation on mortality in HIV infected children aged 1-5 years
- To determine the effect of multiple micronutrient supplementation on weight gain in HIV-infected children aged 1-5 years

Secondary objectives

- To determine the proportion of HIV-infected children aged 1-5 years presenting with subnormal levels of selected micronutrients (vitamins A, C, D, B6, B12, folate and E; minerals zinc and selenium).
- To assess the impact of supplementation on mean serum micronutrient levels in HIV-infected children aged 1-5
- To assess the effect of multiple micronutrient supplementation on incidence of diarrhoea in HIV-infected children aged 1-5
- To determine the effect of multiple micronutrient supplementation on HIV disease progression in HIV-infected children aged 1-5

Study design

This is a double-blinded randomised controlled trial with an active placebo. The study intervention is a micronutrient supplement containing Vitamins A, B1, B2, niacin, B6, B12, C, D, E, Folate; minerals zinc, copper, iodine and selenium. A total of 824 children are to be enrolled in two strata as follows:

Strata 1: 84 children on ARVs

Strata 2: 740 children not on ARVs

The study sites are the paediatric HIV clinics of Mulago Hospital, Mbale

Hospital, Mildmay Centre, Lira Hospital, Masaka Hospital, Mbarara Hospital and Nsambya Hospital.

Progress

A total of 401 children have been enrolled from all the study sites. 30% have completed six months of follow up.

Evaluation of the ultra sensitive P24 antigen assay as an HIV diagnostic method among HIV exposed children in Kampala

Study team: Peter Elyanu, Philippa Musoke, G. Ndeezi, A. Kekitiinwa

Research questions

- What is the sensitivity and specificity of the Up24 Antigen Assay in diagnosis of HIV infection in children under 18 months of age?
- What are the predictive values of the Up24 Ag assay in diagnosis of HIV in children under 18 months of age?

Methodology

This is a cross sectional study of a diagnostic test, in which 300 children to be recruited at Paediatric Infectious Diseases Clinic.

Progress

All 300 children have been recruited, awaiting analysis at CDC

Proposed research

- A randomized trial of monitoring practice and induction maintenance drug regimens in the management of antiretroviral therapy in children with HIV infection in Africa
- Relationship between HIV-1 subtype, antiretroviral response and resistance in Uganda



Future plans

Family Clinic

Background

Family-based care is gradually being recognised as an extremely well-suited model for delivering paediatric HIV care in Africa. Often HIV/AIDS is a family disease whereby an HIV-infected child could have one or both parents also living with the virus. As caregivers are essential for providing children with nutrition, shelter and support in medication administration, experience has shown that the death of a caregiver can lead to precipitous declines in the health of an HIV-positive child. It has been seen that the health of HIV-positive caregivers — especially biological mothers — can decline as they work to support the health of their child while neglecting their own health.

Family HIV Care Pilot Project

In September 2005, the Baylor College of Medicine Children's Foundation - Uganda in collaboration with the Infectious Diseases Institute (IDI) at Mulago Hospital began piloting a family-based HIV care model at the Mulago PIDC. This family-based HIV care clinic operates Thursday mornings and was initially set up to serve 20 families of approximately five people. On this clinic day the children are seen by Baylor College of medicine Children's Foundation - Uganda physicians while their parents are seen in consultation with an internist from IDI. Alternatively, the entire family is seen together by a family physician. It was agreed that the Baylor College of medicine Children's Foundation - Uganda patient would serve as the index case, and that household members would be offered HIV care and treatment services — including HIV screening and ARV treatment when necessary. As of June 30, 2006, a total of 44 family members have been newly screened for HIV through the Family HIV Care project; 16 (36%) of those tested were HIV positive.

The average number of patients seen per Family Clinic day is 15. Although the programme is currently limited to one half day per week, there is potential for significant expansion.

Benefits

Providing HIV care to both child and parent/guardian together has proven popular with Baylor College of medicine Children's Foundation - Uganda patients and their caregivers. Previously a child would get an appointment to come to the Mulago PIDC and the caretaker and would get a separate appointment to go to the Adult Infectious Diseases Clinic (AIDC) at IDI on a different day. Thus the caretaker needed to make two separate clinic visits (one for the child and one for the caretaker). With family-based care, the paediatric patient and caretaker get a joint appointment and make one trip to the family clinic where they both receive clinical services. As a result they spend less on transport and save time for other activities. These benefits can contribute to improved health outcomes for both the child and caregiver. Consequently the demand for family care services far exceeds the current availability.

Challenges

Challenges for family clinic mostly involve expanding the programme given limited staff and space. Currently the Family Clinic meets only one half day each week, and the staff allocated is only 20% of the typical staff found on other clinic days. This means that the Family Clinic only has the capacity to follow approximately 80 patients whereas the demand could exceed that.

Way forward

Given the popularity of the family clinic model, the challenge of limited capacity to see all the families interested in receiving family clinic services could be overcome by re-evaluating this pilot programme and allocating more staff to this initiative. The most pressing staffing needs appear to be in the counselling and nursing areas.



One of the long-term goals for the Baylor College of medicine Children's Foundation - Uganda family clinic model includes providing basic women's health care to both our mothers and female adolescents. HIV-infected women are at significantly higher risk for other sexually-transmitted diseases, vaginal candidiasis and cervical cancer. Papanicolaou (Pap) screening is widely accepted as one of the most successful ways of preventing cancer. The availability of Pap smear has decreased the number of deaths by cervical cancer by over 60% during the years from 1950 to 1980. By providing Pap smears to women receiving care through the Baylor College of medicine Children's Foundation - Uganda we could significantly improve their primary care. The ability to perform a pelvic exam would also enable screening for common STD's and proper evaluation of common symptoms such as pelvic pain and vaginal itching. The Baylor College of Medicine Children's Foundation - Uganda strategic plan for the year 2006 will address these issues through a joint review of this pilot project and the procurement of necessary tools such as a gynaecological examination table with stirrups, vaginal speculums (including paediatric sizes), a flexible light source, potassium hydroxide solution, and a microscope.

Home-based HIV counselling and testing (HBHCT)

This coming year, Baylor College of Medicine Children's Foundation - Uganda will increase its focus on HIV prevention services. One such service is Home-Based HIV Counselling and Testing (HBHCT). Counselling and testing for HIV is well known to be an effective intervention for behaviour change and risk reduction. Baylor College of medicine Children's Foundation - Uganda will continue to offer testing for caretakers, siblings aged below 19 years and other family members. These tests will be carried out at Post Natal Clinic and the Mulago PIDC and satellite clinics in partnership with adult providers.

In addition, Baylor College of medicine Children's Foundation - Uganda will expand its Community-Based HIV Counselling and Testing activities, which allows families to bring their household members to a nearby location on a weekend. Despite making HIV testing accessible through the above services, households of Mulago PIDC patients still have some household members who are yet to test for HIV. HBHCT aims to fill this gap and maximise the number of households who benefit from HCT. In addition to allowing for early diagnosis and treatment, reducing stigma and a reducing HIV infection and re-infection; HBHCT eliminates transportation costs for the family. It also promotes adherence through supporting disclosure within the household setting. The Baylor College of medicine Children's Foundation - Uganda home health team plans to begin HBHCT activities in May 2006, with priority given to households with a patient on HAART.



Voices of children

Disclosure sets you free

By Gordon T.

We children find it hard to disclose our HIV status to our friends. We fear that if we disclose our status, our friends might discriminate against us; and that we won't be loved as before. In addition, sometimes we lack self confidence and knowledge of how to disclose to our friends. All these factors may make us fail to disclose.



When we fail to disclose, we always feel guilty with friends. We do not feel free to share ideas with them because we fear they might discover things we did not want them to know. We even come to hate ourselves.

Parents also fear to disclose to us. Some children do not know that they are living with HIV, because their parents have not disclosed it to them.

When our parents or guardians fail to disclose our HIV status to us, we find it hard to adhere to drugs since we don't know why we are taking them.

When taking drugs without knowing your status, you don't always care whether anyone knows about it or not. We keep telling out everybody about our drugs. Children always bother their parents or guardians with questions regarding why they keep taking drugs. Some parents who are unable to

disclose to their children end up hating such questions, which is not good. Getting ill on and off brings self hatred to children as they get sick repeatedly without knowing why. We come to hate our parents when we discover by ourselves that we have HIV/AIDS and that our parents failed to disclose it to us in time.

In summary, disclosure is important to both parents and children. After disclosure, children adhere better to their drugs since they know why they are taking them. Parents or guardians feel relieved when their children know of their status. Children feel free and can move on with life better. Children have love and trust for their parents as they had been disclosed at the right time.

Being faithful to medicine

By Kisubi Colline

Adherence refers to taking drugs as prescribed. In other words, it means being faithful to the drugs. I will mention some challenges we face in the process of taking drugs, and how they can be solved.

Challenges

Time: Adolescents may want to choose their own time to take medicines, which is not good. Some choose the times without consulting their parents.

Poor care for the medicine: Some adolescents have dirty bags in which they carry their medication. The way they keep their medicines may not be good.

Food: Some adolescents come from poor families so it is not easy to get lunch and supper, yet they need to eat first before taking some of the their medicines. Therefore lack of eats is also a problem to adolescents.

Poor advice: Poor advice from our friends, for example some of them tell us not to take the drugs. Some adolescents go to churches and some of their religious leaders tell them to leave the drugs.

The Solutions

- Adolescents should consult their elders (parents, etc.) about the time for taking their medicines.
- Adolescents should try to keep their drugs where they could not be disturbed by young children.
- Adolescents should be confident and not listen to wrong advice.
- The families should get together with programme sponsors in order to start some projects that might be sources income for rent, food, and clothing because it looks strange to give someone fish every day rather than giving him a net to start his/her own fishing.
- Last but not least, adolescents should consult their counsellors, doctors and nurses at every step as they take the drugs.

ADOLESCENTS, to me adherence is life.

Empowered by the Teens Club

Below are excerpts from the closing speech made by Brian Nganwa, aged 15, during the closing ceremony of the Global Consultation on the Rights of People Living with HIV on Sexual and Reproductive Health in Addis Ababa, Ethiopia, 30 March 2006.

“My names are Brian Nganwa, I am 15 years old and I was born with HIV. I started taking antiretroviral therapy four years ago and I continue to struggle with this difficult and complex livelihood. I stand here to represent the millions of children and adolescents with HIV, especially those at the Paediatric Infectious Diseases Clinic (PIDC) in Mulago Hospital, Kampala, Uganda”

I am 15 years
old and have
lived with HIV
since I was
born

“The PIDC takes care of over 4500 children and adolescents with HIV and has started more than 1200 children on antiretroviral drugs. For this, and other reasons, I wish to thank our doctors, nurses, clinicians, and all the other staff at the PIDC who diligently take good care of us. I also wish to thank all collaborating institutions and donor organisations for their unending support”

“I belong to the Mulago Teen Club, which is a peer support group for HIV positive adolescents. All of us in this club know our sero-status and work together with our counsellors and doctors to practice a safe and productive lifestyle. The club encourages us to delay our age at first sexual intercourse, provides us with knowledge on sex and sexuality, as well as gives us hope for the future”

“The major challenges we face are similar to those faced by young people all over the world: peer pressure, surviving in a changing world, and coping with our growing minds and bodies. The major difference is that we happen to be HIV positive, thus facing additional challenges such as stigma and discrimination, loss of parents or having single parents, lack of education due to poverty, being abused, defiled and denied many rights. The list is endless”

“We need support. We need our questions answered concerning our sexual and reproductive health, and I do hope that many of these questions have been addressed in this meeting. I pray that the final document has clear recommendations on the reproductive health and rights of adolescents”

Once again, I thank you.
‘For God and My Country’





Baylor International trainers conducting an interdisciplinary team of health professionals workshop. The workshop took place at Hotel Africana.





A Home Health Worker teaches an elderly care-taker how to measure a child's ARV dose



Dr. Sebastian Wanless, the Senior Director Medical Research Bristol-Myers Squibb, making a presentation on good clinical practice



Mr. Mbuya P. a Baylor-Uganda Nutrition Assistant, serves clients with nutrition supplements at Mulago PIDC ward 15



