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PATA Newsletter: "It's a wrap" Celebrating the PATA Summit

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1. PATA Summit: team feedback

"That's why we sing PATA PATA PATA PATA
we care for the children
....
Who's going to fight for them?Who's going to care for them?"

These words rang out over the loud-speakers on the opening night of the PATA Summit in Gaborone.
Dr Patrick Oyaro sang a song written for PATA teams which became a huge hit among the PATA clinics. This is what the teams said about the forum:

- **On self and team refection:** "I found this experience very helpful in assessing myself, my team and thinking what we could improve." - Nurse
- **On one thing I learnt:** "Quality Improvement, because at times you can identify a problem but won't have the right tools to solve it." - Counsellor
- **On networking:** "Don't have to reinvent the wheel." - Social Worker
- **On new information:** "I did not know Palliative Care continues even after death." - Pharmacist
- **On teamwork:** "Go alone, go fast; go together, go further." – Forum slogan
- **On the Expert Patient programme:** "The idea of PATA involving Expert Clients is good and it has reduced the stress." - Nurse
- **To improve PATA's work:** "We need more local networks and forums because it makes people feel motivated and involved." - Doctor

2. Challenges in caring for infants as identified by PATA teams

Day 1 of the recent PATA 2011 Summit addressed 'Early Infant Care'. This topic was coordinated by academic committee member and paediatrician at Red Cross Children's Hospital, Dr James Nuttall with Dr Haruna Baba Jibril from Botswana Ministry of Health. We are very grateful to all the guest speakers for volunteering their time and expertise. Their presentations are available on the PATA website (www.teampata.org) and will be documented in the 2011 PATA Proceedings (available in 2012).

What makes the PATA Forum different from other conferences is that the focus on creating **"communities of practice"** where professionals share their experiences and challenges with each other. The information generated in the workshop sessions is significant as it helps us identify systemic challenges.

A total of 41 teams (each consisting of a doctor, nurse, counsellor and pharmacist) deliberated on the challenges in caring for infants under one year of age in their professional group workshops. A summary of the challenges identified is included below.

Challenges identified by the Pharmacists

- **Communication & Adherence:** language barriers, complicated terminology, clients pretending to understand instructions as not to disappoint pharmacist, different care givers, medicine sharing amongst siblings.
- **Storage conditions:** supply, space to keep medicine, hygiene at home.
- **Dosage:** difficult calculations, lack of computer systems, side effects, difficulties with accurate measurements of syrups by caregivers (e.g. the elderly caregivers).
- **Formulation:** must manually calculate amounts needed, crushing of tablets, hygiene, regimen complexity (FDC– syrups dose adjustments), different packaging, generic names, difficulty in assessing adherence especially for liquid formulation.
- **Caregiver:** low motivation, low understanding, often the caregiver is elderly (even when there are younger people in the family), missed appointments (which lead to poor adherence and treatment failure).
- **Multiple nature of treatment** – HIV, OI, TB, etc

Challenges identified by the Doctors

- **Entry:** failure to link PMTCT to paediatric care and LTFU, mothers testing late.
- **Diagnosis:** national guidelines lagging at peripheral sites, little access to virological testing, exposure to dried blood spot testing is not universal, delay in test results (when testing for infection) leading to LTFU, lack of equipment, TB diagnosis difficult in mothers.
- **Treatment:** psychosocial issues, caregivers change frequently, non-disclosure between parents, lack of competence in community health workers, centralisation of care, CHCW attitudes, poor adherence, changing infant feeding guidelines, cultural issues, caregiver adherence fatigue, lack of supplies (ARV), and poverty in communities.
- **Drugs:** legislation lagging, storage facilities, availability of drugs.

Challenges identified by the Nurses

- **Orphaned child living with grandmothers:** preparation of balanced meals, giving of drugs, understanding of drugs, not reporting side-effects, no transport to bring the child for follow-up care, lack of family support.
- **Taking of quality blood samples:** insufficient specimens, compromised sample.
- **Treating children is overwhelming:** manage only due to multiple presentation of illness, depend on caregiver's history.
- **Work overload:** too many patients and not enough staff.
- **Late diagnosis of infants:** late HAART/ARV, late turnaround time for PCR results, some mothers do not come to collect the result.
- **Inadequate drug supply:** lack of paediatric formulations, measurement of the liquid/syrup formulation.
- **High risk of malnutrition:** due to poverty, ignorance etc
- **Young/adolescent mothers**
- **Feeding problems:** side effects of ARVs, lack of dedication, poor circulation of latest guidelines to the health care settings, lack of knowledge of HIV, use of traditional medicines, difficulty to trace the clients, mothers choose formula feeding even though not qualifying according to AFASS criteria

Challenges identified by the Counsellors

- **Lack of recognition for counsellors by other professionals:** no privacy during counselling sessions, burn-out, transport challenges, HCW attitudes towards client results to loss of infant follow up.
- **Labs and testing:** lab errors and false results, caregivers not returning for results, EID DBS results taking long causing stress to mothers, staff have to pay to transport DBS to lab, defaulters increase, no proper system to track patients for results, shortage of kits and drugs.
- **Communication:** contradictory information on exclusive feeding, wrong address or contact numbers makes it difficult to track patients.
- **Breast/mixed feeding:** mixed feeding due to poverty, lack of knowledge and cultural influence, particularly challenging with mentally challenged mothers who require more support.
- **Caregiver discontinuity:** frequent change of caretakers, mother refusing the baby to be tested, family disclosure, lack of economic support due to single motherhood, child-headed households, young mothers lack parental skills.

- **Lack of disclosure by the mother:** frequent changes in the ART drug combination, stigma and discrimination, negative attitude by the mother, lack of training.
- **Shortage of personnel**: inadequate time for counselling sessions, incompetence of HCW, high staff turnover, trained people absent, lack of orientation of doctors (rotational basis).
- **Non-clinic cases:** no ANC visits, home delivery, no routine care, comes to the facility very sick, infants not brought in time for testing.
- **Lack of male involvement in reproductive education:** failure of parents to appreciate the advantages of child spacing as a part of family planning, teenage motherhood, resistance of male involvement in infant care.
- **Non-disclosure:** mother doesn't disclose HIV+ status to family and caregiver of child, lack of support from family members e.g. alcoholism.
- **Poverty:** low socioeconomic status, lack of knowledge about health services provided (due to lack of community outreach)
- **Adherence:** ART combinations make adherence difficult, drug administration by caregivers, follow-up of defaulters, disclosure of HIV status to partner.

3. PATA Team Grids: Quality Improvement Projects

Although the PATA Summit is a very inspiring event, it is after the forum when all the hard works begins. **It all starts with your clinic team grid.** The Quality Improvement session run by Melanie Pleaner helped teams identify goals.

Amino Kano Tertiary Hospital (Nigeria) aims to have 75% of all children between 8-18 years old disclosed to. They plan to do the following to make it a reality:

- Adopt and interpret their own disclosure tools
- Identify and list all undisclosed clients from the clinic record
- Track clients and begin the disclosure process

The **Alert Team (Ethiopia)** plans to initiate an adolescent clinic and have set the following action plan:

- Inform management of the need for an adolescent clinic
- Select adolescent peer educators
- Contact partners for specific adolescent training
- Form teen clubs and organise education sessions on reproductive health
- Assess the progress of adolescent clinic services
- Organise a school friendly schedule for adolescents

The **TASO team (Uganda)** has planned a 12 month project to reduce children's waiting time at the clinic from 6 hrs to 2 hrs. This will involve changes in the clinic systems as well as writing reports to management on the project to facilitate systematic change at other TASO clinics.

Most of the team grids had at least one intervention focussed on improving adolescent care. The team from **Livingstone Hospital (Zambia)** plans to focus on transitioning adolescent to adult care. **CAP Heal Africa (DRC)** plans steps toward creating a teen club and more adolescent friendly services.

So what happens when teams go home? In a recent email **Empilweni Clinic (South Africa)** says that they "plan to present the PATA grid to our whole team at the next meeting. We want to hear their input so that we can tweak them according to the full team's knowledge. We know that without the extended team's agreement and participation, plans could be less fruitful as team vibe would be undermined."

For a full summary of the team goals watch our website for updates. We would like to wish the teams all the best in achieving their goals.

4. Paediatric HIV Care and Treatment Toolkit launched at PATA Summit: Available for download

PATA, South to South, Zoë Life and International Palliative Care Network worked together to develop the 'Paediatric HIV Care and Treatment – A toolkit for African multidisciplinary healthcare teams' which was launched at the PATA Summit.

Feedback from teams who attended a masterclass on using the toolkit was positive. They noted that the toolkit takes into account the challenges that they are facing from the district to the community level. The comprehensive way that the toolkit covers the uses and dosing of many of the available paediatric drugs in Africa was also appreciated.

Some participants commented that the focus on breastfeeding within the nutrition section is very useful considering the need to respect each cultural group's own traditions. Others cited the importance of IMCI (Integrated Management of Childhood Illnesses). The adapted Zoë Life talk tool is a useful tool to start discussion about disclosure with the caregiver and the child.

The toolkit is available for download on www.teampata.org.

5. PATA Expert Patient dinner and discussions

On 15 November 2011, 20 Expert Patient (EP) supervisors from a range of countries met to discuss ways in which to improve the Expert Patient Programme.

Co-ordinated by Roseanne Turner (PATA EP Manager) and David and Jenny Altschuler (One to One Children's Fund), the dinner resulted in some important outcomes. It was agreed that a code of conduct, core competencies as well as guidelines to support EP supervisors in the recruitment and management of EPs should be developed.

Dr Frasia Karua (Sunshine Smiles Clinic, Kenya) described their nationally recognised EP training curriculum and emphasised the importance of sustainability. At their clinic EPs are paid a stipend for the first year while they are being trained, thereafter they remain a resource to the clinic on a less frequent and more flexible basis.

Frank Samwell (Songea, Tanzania) drew our attention to the difficulty in striking a balance between optimally utilising the expertise of Expert Patients, while not overstepping the limits of their roles. Dickson Nenkuseyo (Transmara, Kenya) felt that the existing PATA contract and core competencies have been very helpful, particularly in the recruitment of EPs.

PATA will prepare guidelines on all the above issues and circulate these to the clinics for comment in January 2012. They will then be taken to the EP Review Committee for approval before being printed and circulated to successful applicants in April 2012.

Congratulations to Dickson Nenkuseyo (Transmara Hospital, Kenya), Frasia Karua (Gertrude's Hospital, Kenya) and Refilwe Sello (Baylor, Botswana) who have been elected to the EP Review Committee.

6. Useful 'disclosure to children' website with materials to download

In October, PATA Project Director Melanie Evans joined various stakeholders as part of the "Guideline Group" to start the discussion on developing South African guidelines on disclosure to children. The group identified the need for an online resource of tools and materials that can be used with children, caregivers and to help health care workers.

The Children's Rights Centre in South Africa has launched an online Clearing House of materials and tools to support the HIV & AIDS disclosure process with children. To access these materials go to http://www.hivaidsdisclosure.co.za/

This clearing house also contains examples of tools that illustrate useful practices, links to websites, and other resources that provide further information on issues related to HIV and AIDS disclosure.

If you have developed any tools and materials and would like to include them in the clearing house or if you would like to join the mailing list to keep up-to-date with key developments and debates in this area email: hivdisclosure@crc-sa.co.za.

7. A poem for World AIDS Day, 2011

This moving poem was written by 17 year old South African boy Vusi Mpangane who has lost both his parents to AIDS. It was published in the book 'Touching Rainbows'– Acknowledging the Child's Voice in Palliative Care" and is reproduced here with permission from International Children's Palliative Care Network. To order a copy of the book, contact Sue Boucher at sue@icpcn.co.za or visit www.icpcn.org.uk

HIV & AIDS
by Vusi Mpangane

I am invisible
I am incurable
I am uncontrollable
I am ungovernable

I move from Cape to Cairo
I move from Africa to America
I move throughout the globe
I move by trains, cars, buses and planes, but I like the trucks.

I have taken the world by storm
I have taken the government by surprise
I am an international president
I control you whether you like it or not
ABC will never defeat me
ABC will never protect you
What I want is D and G
Death is my destination and the grave is your resting place.

If you don't abstain
If you are not faithful
If you don't condomise
Death will strike and the grave will be your home.

I am not afraid of nurses and doctors
I turn teachers into patients
I turn doctors into patients
I will put everybody in bed as I like
I have boys working for me
I will send them to kill when I like
TB will do the job and pneumonia will give you the final kick.

Doctors are afraid of me
They will never blame me for your death
They will always blame TB and pneumonia
What you see is just the beginning
You will never believe your eyes and ears
'Cause I will sweep families and friends like dust.

I will keep hospitals full
I will keep mortuaries full
I will keep the graveyards full
I am the champ of champs
I am the undefeated
I am the undisputed world champion disease
I am HIV & AIDS

PATA treatment teams are working together to defeat this ‘world champion disease’ and provide children like Vusi with hope.

Contributors: Melanie Evans, Toast Coetzer, Taru Jaroszynski, Roseanne Turner, Glynis Gossmann and Virgile Mahoro

Join our Facebook page! Search for “Paediatric and Adolescent AIDS Treatment for Africa” or click here or see our website: www.teampata.org