

HIV Nursing matters

A Magazine of the Southern African HIV Clinicians Society



Are children small adults?
Paediatric disclosure
Clinical tips



contents

inside

Editor's note	2		
Message from the President	3		
Conference report	4		
Current issues			
Adolescents: Meeting them halfway	7		
Nurses, HIV and Paediatrics	10		
Patient-centred care for children	14		
Clinical update			
Lipodystrophy in children	18		
Are children small adults?	22		
Clinical tips for nurses	40		
Ethics & Law			
Paediatric disclosure	24		
		Profile	
		Nurse-led HIV services	30
		Policy	
		Improving quality primary healthcare	32
		International experience	
		Integrating HIV treatment into antenatal care	36
		Where to go	42
		What to do	47
		Competition	
		Win a bursary	25
		Day in the life of a Rural Nurse	46

HIV Nursing Matters

focus on paediatric care

on cover

Are children small adults?

Paediatric disclosure

Clinical tips

ed's note



Nelouise Geyer

The children in our communities represent the future generation and the hope that there will be a better future for us all. The fact that the greatest impact of HIV&AIDS is on our children is sad but true. The impact could be that the children's parents are ill or dead, or they themselves could be living with HIV. In all of these events, the right of the children to grow up in a warm, protective family where they experience love, care, security and the opportunity for education are challenged. This makes them the most vulnerable group in our society who requires our protection and assistance. Considering the MDGs and South Africa's progress, we perform poorly in the prevention of the deaths of mothers and babies – this phenomenon is mainly attributed to the high prevalence of HIV in our country. Only a combination of factors can start to turn this tide around, which includes greater access to counselling and testing, diagnosis and treatment that not only enable mothers living with HIV to live longer, but also prevents mother to child transmission of HIV. Nurses and midwives can play an important role in

achieving greater access to treatment, care and support for mothers, infants and their families. Let us all endeavour to protect our children, because:

“One hundred years from now,
It will not matter,
What kind of car I drove,
What kind of house I lived in,
How much I had in my bank,
Nor what my clothes looked like.

One hundred years from now,
It will not matter,
What kind of school I attended,
What kind of typewriter I used,
How large or small my church.

But the world may be. . .
A little better because. . .
I was important in the life of a child.”

Author Unknown

South Africa has taken important steps to turn the tide of mother and infant deaths around. Following the HCT campaign initiated in 2010, there is great emphasis on training nurses and midwives to become NIM-ART practitioners. The pressure is high to get as many practitioners into the field to increase access to treatment and care, but training without mentoring is no training at all. It is essential that the training of nurses and midwives be followed up with adequate clinical mentoring to assist NIM-ART practitioners to become competent and confident to initiate treatment. Nurses and midwives should not be put under pressure to start initiating without the necessary clinical mentorship recommended and supported by the national Department of Health.



HIV Nursing matters

The Team

Editor

Nelouise Geyer

Message from the president

Professor Francois Venter

Editorial Advisory Board

Dr Elizabeth Makoka

Ms Stacie Stender

Dr Natasja Davies

Dr Liesl Smit

Ms Laurie Schowalter

Ms Fatima Shaik

Contributors

Monument Trust

Advertising

Fatima Shaik

SA HIV Clinicians Society

Tel (011) 341 0162

For more information contact

SA HIV Clinicians Society

Suite 233 PostNet Killarney

Private Bag X2600

Houghton

2041

www.sahivsoc.org

Tel: +27 (0) 11 341 0162

Fax: +27 (0) 11 341 0161

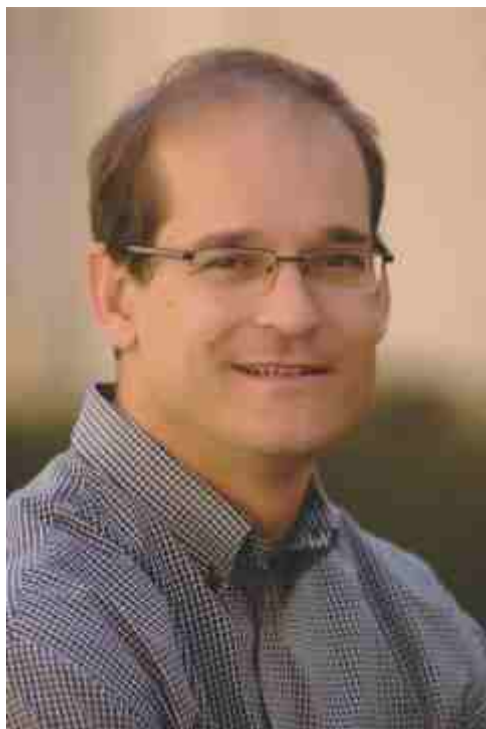
e-mail: sahvivsoc@sahivsoc.org

Article/letter submissions:

nelouise@sahivsoc.org

The opinions expressed are the opinions of the writers and do not necessarily portray the opinion of the Editorial Staff of **HIV Nursing Matters** or of the **Southern African HIV Clinicians Society**. The **Society** does not accept any responsibility for claims made in advertisements.

All rights reserved. No part of this publication may be reproduced in any form without prior consent from the editor.



Prof Francois Venter


Message from the president

PMTCT
programme has
resulted in the
number of
children being
at a record low

This edition focuses on children and adolescents – and comes at a time when data from the national PMTCT programme demonstrates that the number of children contracting HIV is at a record low.

This is great news – it's bad enough hitting your teens, without having to deal with the emotional stress of having a pre-existing sexually transmitted disease, just as your sexual awakening is happening.

On top of this, we still have a large number of AIDS and other orphans who will require high levels of psychosocial and financial support.

The fact that the tap has been turned almost off at source is good news, so that we can get children tested. Then we need to get those who are infected swiftly on to treatment, deal with the psychological needs of these HIV-infected children, and prepare them for adulthood. 

Paediatric report

from the 6th International AIDS Society Conference and the 3rd International Workshop on HIV Pediatrics

Polly Clayden HIV i-Base



The biannual International AIDS Society (IAS) meeting is more focused on scientific developments than the World AIDS Conference and considerably smaller but there is still a huge amount of data presented there (including that on paediatrics).

All the abstracts, most of the posters and presentations are online.

<http://pag.ias2011.org/PAGHome.aspx>

The International Workshop on HIV Pediatrics immediately precedes the IAS meetings. This small annual meeting is now in its third year and becoming quite established. Although abstracts are often submitted to both meetings, in this one they may often get an oral presentation instead of just a poster. For those specialising in paediatrics this meeting is a welcome opportunity to present and discuss work in a dedicated forum. Abstracts and presentations are online.

http://regist2.virology-education.com/abstractbook/2011_8.pdf

http://regist2.virology-education.com/2011/3HIVped/15_July.html

This report includes a few studies from both meetings with implications for Southern Africa.

No difference in AIDS-free survival in children starting ART with a CD4 between 15% and 24% compared to deferring until less than 15% in the PREDICT trial

Information to guide initiation of treatment in children older than one year of age is scarce.

Results from the PREDICT trial - presented as late breakers at both meetings - found that



deferring ART until CD4 count fell below 15% or the occurrence of CDC category C events did not affect AIDS-free survival in children compared to starting antiretroviral therapy (ART) at a CD4 percent between 15% and 24%. [1]

PREDICT was conducted in 299 children from nine sites in Thailand and Cambodia between April 2006 and September 2008. Children were randomised to receive immediate ART or defer until their CD4 reached less than 15%. The children's baseline characteristics are shown in Table 1.

The primary endpoints were AIDS free survival at week 144 and neurodevelopmental outcome by Beery visual motor interrogation test.

Table 1: Baseline characteristics of children in the PREDICT trial

Parameter	Immediate arm (n=149)	Deferred arm (n=150)
Age (years)	6.4 (3.7-8.0)	6.4 (4.2-8.7)
Female	77 (52%)	96 (64%)
Thai: Cambodian	90:59	89:61
CD4%	19 (16-22)	20 (17-23)
HIV RNA (log 10)	4.9 (4.4-5.0)	4.7 (4.3-5.0)
Weight-for-age z-score	-1.3 (-2.0 to -0.8)	-1.3 (-2.0 to -0.8)
Height-for-age z-score	-1.6 (-2.5 to -0.8)	-1.7 (-2.6 to -0.9)

Age, CD4%, HIV RNA, weight-for-age z-score and height-for-age z-score are mean values.

Retention was high in this study (96%). At week 144, 69 (46%) children had started ART with a mean CD4 at initiation of 13.8%. Of these, 17 children were less than 5 years and had a mean CD4 count of 591 cells/mm³ and 52 children were older than 5 years and had a mean CD4 count of 309 cells/mm³.

AIDS-free survival was high, 97.9% in the immediate arm and 98.7% in the deferred arm. The incidence of CDC C events or death per 1000 person-years

was 7.6 in the immediate arm and 4.9 in the deferred arm. The incidence of CDC category B events per 1000 person-years was broadly similar in both arms, 88 in the immediate arm compared to 110 in the deferred arm. But there were more episodes of herpes zoster (2 vs 13) and thrombocytopenia (1 vs 10) in the immediate and deferred arms respectively. There were only two episodes of TB, one in each arm. Weight for age z-score was similar, deferred vs immediate -0.12 p=0.074. But children grew at a slower rate in the deferred arm, height for age z-score, deferred vs immediate -0.23, p=0.003. And at 144 weeks of follow up there was no significant difference by Beery visual motor test between the two arms; Beery score deferred vs immediate, 84.7 vs 86.8, p=0.5. The investigators found that at approximately three years of follow up, the rate of progression to AIDS was extremely low in both the immediate and deferred arms. The finding reflects a slow disease progression among HIV-infected children who survive the first year of life without treatment. This study is important and a bit of a surprise to many as it appears to contradict both adult data and that for young infants. But the median age in the study reflects a population that have survived without treatment for the first few years and therefore selects a group of healthier children without rapid disease progression.

More metabolic abnormalities in children receiving a PI compared to NNRTI in the NEVEREST study.

NEVEREST was a study, conducted in South Africa, in which young children who were exposed to nevirapine as prevention of mother to child transmission (PMTCT) and initiated on PI-based ART were randomised to continue on this regimen or switch to a nevirapine based regimen. NEVEREST investigators looked at body composition and metabolic abnormalities in 156 children exiting the trial. The objectives were to compare lipid profiles, markers of inflammation and regional fat distribution in children receiving a PI-based regimen of lopinavir/ritonavir (LPV/r) plus 3TC plus d4T to those switched to an NVP-based regimen. [2]

The children's weight (kg) and height (cm) was measured and weight-for-age, height-for-age and BMI-for-age z-scores (WAZ, HAZ, BAZ) calculated. Fasting total cholesterol (TC), high density lipoprotein (HDL), low density lipoprotein (LDL), triglycerides (TG), C-reactive protein (CRP), viral load, absolute CD4 and CD4 percentage were obtained. Circumferences and skinfolds were also measured; waist to hip ratio (MWC:MHC) and skinfold sum (SFS) were calculated. Upper arm and thigh fat estimates (UFE, UTFE) were calculated by Rolland Cachera. Analyses were intent to treat. At the time of analyses, children were a mean age of 5.1 years and approximately half were boys; 85 (42 boys) were randomised to the PI arm and 71 (40 boys) to the NNRTI arm. There were no differences between the two groups in sex, age, total time on ART, time since randomisation, WAZ, HAZ or BAZ or proportion with viral load <50 copies/mL. But children in the NNRTI group had a higher CD4 count, 1480 cells/mm³ compared to 1356 cells/mm³, p=0.049. The investigators found differences in metabolic measurements. Mean TC was greater in the PI group, 171 mg/dL vs 161 mg/dL, p=0.05, as was the proportion of children with hypercholesterolemia (TC >200 mg/dL), 18.8% vs 8.5%, p=0.03. They also observed lower mean HDL levels, 51 mg/dL vs 59 mg/dL, p=0.006 and higher mean LDL levels, 100 mg/dL vs 88 mg/dL, p=0.018, in the PI group. The mean TG level was also greater in the PI group, 94 mg/dL vs 72 mg/dL, p<0.001 as was the proportion with hypertriglyceridemia (TG >150 mg/dL), 12.9% vs 2.8%, p=0.038. The children in the PI group had significantly greater amount of total body fat compared to those receiving an NNRTI, with a mean SFS of 43 mm

vs 39 mm, $p=0.029$ and % body fat by BIA of 0.17 vs 0.14, $p=0.042$.

The percentage of fat in the upper arm did not differ between groups but the percentage of fat in the upper thigh was greater in the PI group, $p=0.021$. Also the PI group had a smaller ratio of trunk fat relative to thigh fat, $p=0.03$.

The investigators wrote: "These unfavourable alterations in lipids and lipoproteins are of great concern with respect to potential increase in long term CVD risk and should be considered in treatment strategies, such as the reuse of NNRTIs for NNRTI-exposed infants".

These findings are important for South Africa as all children less than three years old start treatment with a PI based regimen.

Prematurity not associated with early mortality in infants on ART

Prematurity is a known risk for infant mortality. Other risks include maternal immunosuppression, delayed initiation of ART and low baseline CD4 percentage.

Investigators from the Perinatal HIV Research Unit (PHRU) in Soweto, South Africa showed findings from a cohort study designed to investigate prematurity among children born in 2009 and initiated on ART before one year of age. The study was a database and record review.

The background characteristics of the infants at time ART initiation are shown in Table 2.

Table 2: Background characteristics of term vs preterm infants at ART initiation

	Preterm (n=31)	Term (n=114)	p-value
Median age weeks (IQR)	8.5 (7.4 - 13.1)	9.9 (7.9-15.1)	0.19
Median Cd4% (IQR)	26.6 (19.7-32.7)	31.5 (22.4-39.5)	0.025
Median Cd4 cells/mm ³ (IQR)	1820 (1194-2409)	1768 (1217-2497)	0.87
Viral load log copies/mL (IQR)	5.9 (5.69-5.88)	5.9 (5.75-5.88)	0.89
Exclusive formula feeding (%)	24 (80%)	88 (79%)	0.93

The investigators reported no difference in mortality between preterm and term infants, respectively, 3% vs 4%. Lost to follow up was 8% overall. Univariate analysis revealed non-significant p-values for all variables ie preterm vs term, baseline CD4 percentage, baseline viral load, breast vs formula feeding and maternal PMTCT. The investigators noted the small sample size and that the mortality rate was low in this study. They concluded that although HIV-infected preterm infants have significantly lower CD4 percentage than term infants, with early ART initiation they are not at increased risk of mortality.

Virological outcomes in South African children treated with ART and anti-TB therapy

Rifampicin reduces plasma concentrations of PIs in both adults and children. Dose adjustment is complicated in young children and this can lead to virological failure.

Investigators from Stellenbosch University and University of Cape Town looked at virological outcomes among children 13 years old or less receiving ART with or without anti-TB therapy at Tygerberg Hospital, Cape Town. This study was a retrospective review of hospital records.

In this cohort, children receiving LPV/r received ritonavir (RTV) as a single PI during their TB treatment. Viral load was measured at baseline and every six months in the study and failure was defined as viral load >5000 copies/mL on two consecutive measurements. The investigators evaluated a total of 218 children, of these 79 were in the co-treatment group and 139 in the group receiving only ART.

They found that children in the co-treatment group were younger, with a median age of 21 months compared to 36 months in the ART group, $p=0.0006$. Children in the co-treatment group were also more malnourished, with a median WAZ of 3.27 compared to -1.87 in the ART group, $p<0.0001$. But there were no differences in baseline CD4 or viral load between the two groups. More children in the co-treatment group received PI-based ART, 72% compared to 42% respectively, $p<0.0001$.

The evaluation revealed that co-treatment was a significant predictor for

virological failure, OR 2.73, $p=0.003$. Older children and children who were not on a PI-based regimen did better in this group. PI-based ART increased the odds of failure by 4.3 times in the co-treated group compared to the children receiving only ART. Younger age and PI based ART also quickened the time to failure, irrespective of TB. In the co-treated group, the timing of TB (before or after starting ART) did not have an effect on the odds of failure. Overall younger age and TB co-treatment were strong independent predictors of failure in this analysis. The investigators noted that their findings were most likely related to the use of RTV as a single PI in the co-treated group. They added that "super-boosted" (increasing the boosting dose of RTV) LPV/r performs better in young children with TB, but more data are needed. They concluded that: "Aggressive strategies for the prevention of TB in this vulnerable population are urgently needed."

References

1. Puthanakit T et al. Randomised clinical trial of immediate versus deferred antiretroviral therapy initiation in children older than one year with moderate immunodeficiency: the PREDICT Study (NCT00234091). 3rd International workshop on HIV paediatrics. 15-16 July 2011. Rome, Italy. Oral abstract LB 01. Also presented at the 6th IAS Conference on HIV pathogenesis, treatment and prevention. 17-20 July 2011. Rome, Italy. Poster abstract TULBPE023. <http://pag.ias2011.org/Abstracts.aspx?AID=4776>
2. Shiao S et al. Body composition and metabolic abnormalities of perinatally HIV-infected children in South Africa on long-term ARV treatment. 3rd International workshop on HIV paediatrics. 15-16 July 2011. Rome, Italy. Oral abstract O_2. Also presented at the 6th IAS Conference on HIV pathogenesis, treatment and prevention. 17-20 July 2011. Rome, Italy. Poster abstract 252. <http://pag.ias2011.org/Abstracts.aspx?AID=760>
3. Lazarus E et al. Prematurity is not a risk factor for early mortality in HIV-infected infants on antiretroviral therapy. 3rd International workshop on HIV paediatrics. 15-16 July 2011. Rome, Italy. Poster abstract P_18.
4. Walters E et al. Virological outcomes in South African children co-treated with highly active antiretroviral therapy (HAART) and anti-tuberculosis therapy. 3rd International workshop on HIV paediatrics. 15-16 July 2011. Rome, Italy. Oral abstract O_20.



Adolescents: Meeting them halfway

Shanaaz Kapery Randeria, Adolescent Project Coordinator, Harriet Shezi Children's Clinic
Chris Hani Baragwanath Hospital, Soweto



The mere mention of the word 'adolescent' or 'teenager' is enough to cause panic. Working with teenagers can be equally daunting. However, there are effective ways to communicate, live with and have meaningful relationships (personal

and professional) with adolescents. The key is to understand the adolescent stage of development, and thereafter to use this information to make the interaction with the teenagers less turbulent and volatile.

The Adolescent stage of Development: Erik Erikson's Developmental Stages of Development:¹

Erik Erikson describes the healthy development of an individual from birth to late adulthood through the transition of 8 developmental stages. During each stage of development, the individual will be confronted with tasks that need to be mastered before progressing onto the next stage. Effective completion of the stages will ensure that challenges related to that stage do not reappear later on as problems.

Erikson describes the adolescent stage of development, 'Identity vs. Role Confusion' from ages 13-19 years. The main developmental tasks, according to Erikson, of adolescence are:

- Formation of a personal, integrated identity
- Formation of a school or occupational identity (career choice)
- Formation of a sexual identity at a later stage of adolescence
- Pondering the roles they will play in the adult world

Teenagers find this transition from 'Childhood' to 'Adulthood' difficult because adulthood brings with it tremendous material, physical, emotional and occupational challenges and demands.

Decisions, value systems and choices were previously made by adults for children; but the adolescent wants to and has to do all of this on his/her own. In order to do this he/she has to master many skills to emerge an effective, independent and functional adult in a very unpredictable world.

Research, by Cluver et.al², indicates that mental health issues like depression and anxiety are higher in HIV positive adolescents. The rapid

physical and chemical changes and cognitive development at this stage is a major contributor to stress and anxiety for adolescents. Other stressors for teenagers can be having to deal with trauma for example learning of their HIV positive status, bereavement and loss (of family member, friendships, future and dreams because of HIV, etc.), peer pressure (sex, drugs and alcohol), changes in physical appearance (acne, changes in body shape and voice) and managing conflict with caregivers.

All of these changes often result in mood swings, argumentativeness, isolation from parents/caregivers, reverence and desirability of peer group affiliations and A-T-T-I-T-U-D-E!

Working with Adolescents:

Briefly, I work at a paediatric HIV/AIDS clinic, the Harriet Shezi Children's Clinic (HSCC) in Soweto³. The psychosocial program is facilitated by me and a team of counsellors who counsel and do group work (open and closed) with caregivers, children and adolescents. Most patients are perinatally infected orphans, presenting with anxiety, depression and/or poor school performance; living with a grandmother in a financial- and food- insecure environment.

Children's Rights and Child Participation (CP) are integral components of my programs. Children's Rights acknowledges and accepts adolescents as individuals, whose voices are heard in matters relating to them. This is often in conflict with caregivers' culture and belief that a 'children should be seen and not heard', essentially closing the door on communication.

Child Participation implies that needs of the adolescent and what he/she wants are heard and taken into

consideration; coupled with the Rights of the Child it gives meaning and a sense of purpose to adolescents.

Contrary to popular belief, observing the Rights of the Child does not necessarily mean that caregivers relinquish their authority over or right to discipline the adolescent. Rather, the responsibilities that accompany Children's Rights imply that adolescent must take ownership of his/her behaviour and its consequences.

During adolescent focus group discussions and support groups four themes emerge consistently: communicating with caregivers; dating, sex and having families of their own; the need for autonomy and peer pressure (and the value of belonging to a group).

Adolescence is the stage of sexual awareness, awakening and experimentation (forming a sexual identity). Adolescents who are HIV positive find this particularly anxiety-provoking. A possible explanation for this could be that HIV impacts significantly on the sexual aspect of our lives. Adolescents spend a lot of time dreaming and thinking about having families of their own in the future. Programs that include Sexual Reproductive Health components, which cover 'Pregnancy' and 'Prevention of infecting HIV negative partners' are particularly well received by adolescents. There are many members of staff in health care settings who are experienced and willing to offer these discussions, even in resource-limited settings.

So, what do adolescents need?

There is only one way to know this for sure - ask them. Programs and discussions are almost guaranteed to fail if the adolescents are not

consulted on what they need. Focus group discussion and support groups are good forums for gaining this information.

Information gathered from adolescents indicate that they need their caregivers to trust them, to accept that they are no longer children, that they are capable of making informed decisions and choices, to be treated with respect, to be given autonomy, freedom to spend time with their friends, space from caregivers but confidence that the caregiver will be available to provide love, care and support when they need it. Incidentally, research indicates that social support has a positive impact on mental health and adherence to medication. There is also an unrealistic expectation from adolescents that caregivers should intuitively know what they need despite the fact that they do not communicate effectively with their caregivers about their needs. Debating and information forums, where adolescents and their caregivers can communicate their needs to each other in a safe and respectful environment, are also useful. Both adolescents and caregivers comment on how much these forums have helped them in understanding and communicating with each other.

It is easy to assume that adolescents no longer need their caregivers since they strive so hard to obtain autonomy and distance from them. This is only partly true because adolescents still need their caregivers, but their needs have changed. Older adolescents would comment that they want their caregivers to be with them when they are taking their antiretroviral medication, or that caregivers don't enquire about their health if they are HIV positive; adolescents want to feel that they play an important role in decision-making; they want to be

treated with respect and dignity by caregivers and family, medical staff, teachers and peers. Peer pressure is at its peak during adolescence because of their need to belong and to dissociate from caregivers and form their own identity. Questions adolescents often ask are: How do I leave a group of friends? How do I find a new group of friends? How do I make it easier to leave a group of friends?

Providing fun leisure and recreational activities, financial and food security and attending school were also mentioned as adding value to teenagers' lives. What they did not want or need was to fulfill parenting roles and responsibilities and as a result time that should be spent on schoolwork and activities to be compromised.

What works for Adolescents?

Adolescents acknowledge that culture plays a big role in communicating with caregivers. In our efforts to equip adolescents with life skills and tools to face challenges and resolve them, various aspects have been included in programs. These include teaching adolescents good communication skills; respecting and acknowledging that one's culture and beliefs are important, but that it is acceptable to question culture and belief systems if they are disadvantageous, harmful or oppressive; creating an environment of unconditional acceptance and support; equipping them with life skills and tools to combat bullying, peer pressure, negotiating safer sex practices and self defense; and problem-solving skills. Basically, giving them the tools and allowing them to run with it.

So now what?

Teenagers require our empathy and that we not take their behavior personally. They have many difficult

tasks to master to be functional, effective and self-sufficient adults. Adults sometimes find their roles and responsibilities daunting and overwhelming; for a teenager, without life experience to guide them, this is even more so. Also remember that the teenager's ability to analyze and question intentions is a new-found ability, which should be used.

Argumentativeness is therefore not necessarily a sign of disrespect - it is a normal part of development. Verbal and non-verbal messages about sex, sexuality and intimacy are important when dealing with adolescents. The awakening of the adolescent's sexuality and formation of a sexual identity is very much influenced by these messages. Trusted adults need to have open and honest communication about sex and sexuality with adolescents. Most importantly, the teenagers have to amalgamate aspects from earlier stages of development with what they envisage for the future when forming an identity. This will allow them to create an individual they are comfortable with and accepting of; not whom we think they should be!

References:

1. Erikson, E.H. (1968). *Identity: Youth and Crisis*. New York: Norton.
2. Lucie Cluvera,b*, Frances Gardner and Don Operarioc. *Poverty and psychological health among AIDS-orphaned children in Cape Town, South Africa*, * [a Department of Social Policy and Social Work, University of Oxford, UK; b Cape Town Child Welfare; c Department of Community Health, Brown University, USA. (Received 7 March 2008; final version received 29 September 2008)]
3. Nokuthula L. Skhosana; Helen Struthers; Glenda E. Gray; James A. McIntyre. 2006. *HIV disclosure and other factors that impact on adherence to antiretroviral therapy: the case of Soweto, South Africa*. *African Journal of AIDS Research*, 5(1).



Nurses

HIV and Paediatrics

Liezl Smit, Carolin Diergaardt, Stephanie Fourie, Nombulelo Matshikwe, Mabjale Letsoalo
South to South Program for Comprehensive Family HIV Care & Treatment (S2S), Stellenbosch University

"Nurses are the backbone of healthcare systems everywhere in the world."

2011 Nursing Summit, Gauteng, South Africa

"History will judge us on how we respond to the AIDS emergency in Africa... whether we stood around with watering cans and watched while a whole continent burst into flames.... or not."

Bono

"There can be no keener revelation of a society's soul than the way in which it treats its children."

Nelson Mandela

"Children are one third of our population and all of our future."

Select Panel for the promotion of Child Health 1981

The Global Impact of HIV

Despite unprecedented commitment and notable achievements in the fight against HIV/AIDS over the last 10 years, 33.3 million people are infected worldwide with HIV, and new infections continue to outpace the number of people being placed on antiretroviral treatment.

Sub-Saharan Africa accounts for 68% of the global prevalence of HIV. Women of childbearing age are disproportionately affected with women, mostly from poor communities, accounting for 60% of the adult HIV prevalence. This affects whole families and communities, and increases the risk of childhood undernutrition and death; even in HIV negative children.

HIV is the leading cause of mortality among women of reproductive age. The mother's health is the key to the child's health and survival. Children born to HIV infected mothers have a 3-5 times higher risk of death regardless of their HIV status. Women with advanced HIV disease are not only more likely to transmit HIV to their infants, but these infected infants are more likely to die by 6 months of age. The number of children who have lost one or both parents to HIV in Africa already exceeds 12 million.

Globally the number of new HIV infections among children has decreased significantly; 5,000,000 infant infections in 2001 compared to 370,000 in 2009. This decrease is thanks to expanded PMTCT programmes. However, many more of these infections could have been prevented; only 53% of pregnant HIV infected women had access to antiretroviral treatment to PMTCT of HIV in 2008.

Over 2 million children under the age of 15 years are infected with HIV worldwide, mostly through mother to child transmission (MTCT). At least 90% of these children live in sub-Saharan Africa. Without appropriate treatment, it is estimated that 50% of children infected will die before the age of two. HIV-infected children under one year of age are among the most vulnerable. HIV remains one of the leading causes of under-five mortality in low and middle income countries. The HIV epidemic reversed previous gains made in child survival. An estimated 260 000 children

under fifteen died due to AIDS in 2009 and only 28% of eligible children under fifteen actually received Antiretroviral Treatment (ART).

Early identification of paediatric HIV infection and prompt initiation of ART has been shown to reduce deaths by 76%. With access to ART, good outcomes in HIV infected children have been documented with probability of survival one year after the start of ART ranging from 84-97%.

Guiding principles for HIV care and treatment for children

- 1. Urgency.** HIV prevention, diagnosis, care and treatment must be immediately scaled up to avert unnecessary deaths in children exposed to or infected by HIV.
- 2. Universal access.** All children in need should have access to HIV prevention, diagnosis, care and treatment services.
- 3. Life-long care.** HIV is a chronic disease and requires ongoing care and treatment; national governments have a responsibility to ensure uninterrupted care and treatment.
- 4. Family-centered care.** Family members should receive care in a manner that recognizes and responds to the family as a unit.
- 5. High quality care.** Care provided should be of the highest quality possible and should be monitored and improved through a system of improvement.

Scale up of HIV related prevention, diagnosis, care and treatment for infants and children, a Programmatic Framework. WHO and UNICEF, September 2008

South Africa, 'Departing for a better future'

South Africa has the largest HIV burden of any country in the world, with an estimated 6 million people living with the virus. In 2009, almost 30% of pregnant women in SA were infected with HIV.

Life expectancy has reduced almost 20 yrs (men 50 yrs, women 54 yrs). South Africa is one of only 12 countries in which under 5 child mortality has increased since 1990 with no improvement in maternal mortality over the same time period. This means that South Africa is not on target for reaching the Millennium Development Goals (MDG) 4 and 5 to reduce under-five and maternal mortality by 2015. With HIV being the leading cause of mortality, most of these deaths are preventable if individuals access appropriate treatment. HIV/AIDS was responsible for 57% of all child deaths and more than 80% of deaths after 28 days and before 5 years. Avoidable factors in the health system (administrative support or poor clinical care) accounted for 75% of child deaths and 78% of maternal deaths.

Identification of HIV in children is vital to ensure timely access to care. Many of the children dying each day have either not received an HIV diagnosis or been initiated on ART. Opportunities abound for testing and diagnosing HIV in children attending under-five primary healthcare (PHC) clinics, TB services, paediatric in- and outpatients, as well as children of adults attending VCT services or HIV care and treatment programmes (especially nutritional), but these are often missed.

South Africa is home to the largest ART programme in the world and consequently the largest number of children accessing chronic lifesaving ART care of children on chronic lifesaving ART. In 2009, approximately 86,270 children had ever been initiated on ART. This represents an estimated antiretroviral coverage rate of 54% amongst those in need. Despite success in the rapid expansion of the paediatric ART program since 2006, achievements have been made largely in referral hospitals using a care delivery framework dependent upon specialist paediatric consultants. Thousands of HIV-infected children in rural and peri-urban communities continue to have a diminished chance for healthy outcomes due to the lack of decentralization of paediatric ART care to primary healthcare level facilities.

On December 1, 2009 President Zuma announced South Africa was to embark

on a massive effort to expand antiretroviral care for both adults and children to the primary healthcare facility level to 'ensur[ing] that all health institutions in the country are ready to receive and assist patients and not just a few accredited ARV centers'. South Africa thus followed in the footsteps of many other countries, particularly those addressing a generalized HIV epidemic, which have begun to decentralize HIV treatment to primary health care (PHC) centres with the ultimate goal of universal access to HIV treatment.

Nurse initiation and management of patients on ART (NIMART) was identified as a key strategy to obtain this goal.

The Role of Nurses in ART provision

Nurses have always been in the front-line responding to the health needs of children, providing hands on care to patients and comfort to families on a daily basis. This includes maintaining good nutritional status, providing early and vigorous treatment for common paediatric infections, immunization according to standard schedules and the assessment and support of families to care for the child.

A lack of doctors and the traditional holistic role played by the nurse means that they will continue to have a central role to play in not only ensuring universal access to ART for patients in need, but also in the primary prevention and the timely identification of HIV infection.

Evidence for successful non-physician provided ART in Africa and South Africa, with equivalent ART treatment outcomes in terms of viral load suppression, mortality and retention in care, have been reported. These studies however relied heavily on intensive training and support from non-government organisations, and in many, non-physician care was restricted to the monitoring of patients already on treatment.

Cohen et al reported that the provision of ART to children by nurses at primary care level in Lesotho was feasible and effective, and did not require the presence of paediatric specialists. The

enrolment of children lagged behind those of adults though due to a lack of reported confidence and skills in nurses and intensive external training was provided.

Van Griensven et al reports similar success in the treatment of children from two nurse lead health centres in Rwanda. Key elements of the successful scaling up of ARVs were highlighted as adequate numbers and training of nursing staff. This model relied on an increase and retention of nursing staff through a financing system, shifting of traditionally nurse performed tasks to new or reinforced cadres (administrative support, data capturing and monitoring, counselors and community support groups and lab staff for blood collection) and clear protocols for indications for referrals. Ongoing training and supervision was ensured by having one full time equivalent physician per health centre, visiting the health centres at least 2-3 times a week.

Early qualitative results from the STRETCH (Streamlining Tasks and Roles to Expand Treatment and Care) trial in the Free State, South Africa, suggests that although NIMART is feasible and acceptable in the public sector, an incremental approach to implementation, including an initial phase of external training and support; and clinical guidelines tailored to nurses at different level of care, are needed. The authors caution against the risk of expecting nurses to carry the ongoing burden of rapid treatment expansion without adequate training or support within a health system already under significant strain.

Implementing Paediatric NIMART in South Africa

Integrated Management of Childhood Illness (IMCI) is a WHO/UNICEF strategy to improve child survival in resource poor settings. It consists of clinical algorithms which are used by first level health workers to assess and treat all ill children below the age of five years at first level facilities (primary health care facilities). It offers a comprehensive approach to the care of the ill child, which ensures appropriate and combined treatment of those diseases which account for the majority of child deaths.

With the rise of the HIV pandemic, the

IMCI guidelines were adapted to include identification and management of HIV infected and exposed children; and then again in 2010 to include ART initiation and follow up steps. These guidelines clearly define criteria for nurse initiation and follow up vs referral to the next level of care.

IMCI training, coupled with targeted mentorship to ensure adequate skills and knowledge of nurses to initiate and manage children, is the preferred methodology for the implementation of paediatric NIMART in South Africa. Despite these National Department of Health directions, paediatric NIMART lags significantly behind those of adults.

Barriers to implementation of paediatric NIMART observed are:

- Inadequate staffing with no clear policies on shifting tasks to other health cadres to ease the burden on nurses now expected to provide comprehensive HIV services
- Uncoordinated training and mentorship programs not targeting nurses earmarked for ART initiation
- Inability of nurses to practice new skills after training due to a lag in policy to allow ARV prescription by nurses
- Persistent perceptions that paediatric specialists or experienced general practitioners are required for paediatric ART initiation
- A delay in the national availability of the revised IMCI chart booklets
- Doctors identified as mentors for nurses are not experienced in either the IMCI methodology or paediatric ART
- Lack of pharmacy support package (paediatric drugs, supply chain etc.) and
- Poor integration between health services, resulting in late identification of children infected with HIV or late referral for access to treatment.

Despite these barriers, most primary health care nurses are willing to initiate ART at their facilities with the correct amount of training and support.

'As we have started the past few months to initiate ART, still I feel comfortable and more competent to initiate ART in adults, not children because they are more complicated. I think I still need the Doctor to mentor me, especially on the interpretation of results such as Viral load, CD4 count percentage and WHO Clinical staging. I feel with supervision of the doctor, soon I will start to initiate ART to stable children who are in need. Currently we are having 22 children who were already initiated on ART and they are doing well.

And it is good enough to us as nurses to initiate ART because we are able to establish good relationship with the clients and really enable them to adhere to treatment or discuss any difficulties if there is that trust between me and them'.

Professional Nurse, Cyferskuil ART

Conclusion

Children have historically faced significant and disproportionate barriers to accessing life-saving antiretroviral care. The expansion of ART to primary healthcare level and integration of comprehensive paediatric HIV care into IMCI offer an opportunity to drastically reduce health inequities of this underserved population. It is important that every effort must be made to accelerate the implementation of paediatric NIMART and to provide continuous mentorship to nurses to ensure confidence and competence in the initiation and management of ART in children.

Enrolling pregnant women and children into HIV care and treatment early and regularly can prevent new HIV infections and reduce morbidity and mortality, effectively sustaining the quality of life of mothers, their children, and their families.

Early enrolment

of pregnant women + children into HIV care can prevent new HIV infections, reduce mortality and morbidity, and sustain quality of life

Decentralisation entails the implementation of comprehensive HIV counseling and testing and care and treatment services at first levels of health contact.

To implement this, the following are required:

1. Policies allowing non-physicians to initiate and monitor treatment
 2. Scaled expenditure for ART services at PHC centres
 3. Development of a health workforce comfortable with and skilled in initiating and monitoring treatment, including treatment services for pregnant women, infants and children
 4. Effective forecasting, procurement, and supply chain management of antiretroviral drugs, cotrimoxazole, and drugs for managing opportunistic infections
 5. Expanded laboratory capacity to monitor treatment
- Mulamba D, Fullem A, Hirschhorn L, Allers C, Oser R, Rau B. *Decentralizing Antiretroviral Treatment Services at Primary Health Care Facilities; A guide to expanding access in resource-limited, generalized HIV epidemic settings. Arlington, Va.: USAID | AIDSTAR-One Project, Task Order 1, 2010.*

¹Global Report: UNAIDS report on the global AIDS epidemic 2010. Geneva, UNAIDS, 2010

²WHO, UNAIDS and UNICEF, Towards Universal Access: Scaling up priority HIV/AIDS interventions in the health sector. Progress Report 2010 (Geneva: WHO Press, 2010). Available online at <http://www.who.int/hiv/pub/2010progressreport/report/en/index.html> (Accessed December, 2010).

³L. Kuhn et al. "Does Severity of HIV Disease in HIV-Infected Mothers Affect Mortality and Morbidity among Their Uninfected Infants?" *Clin Infect Dis* 41, no. 11 (2005): 1654-61.

⁴Joint United Nations Programme on HIV/AIDS (2008) 2008 Report on the Global AIDS Epidemic. http://data.unaids.org/pub/GlobalReport/2008/JC1511_GR08_ExecutiveSummary_en.pdf. (Accessed May, 2011).

⁵Newell, Marie-Louise, et al., Mortality of Infected and Uninfected Infants Born to HIV-Infected Mothers in Africa: A Pooled Analysis. *Lancet* 364:1236-43, 2004.

⁶Paediatric HIV Prognostic Markers Collaborative Study Group. "Short-Term Risk of Disease Progression in HIV-1-Infected Children Receiving No Antiretroviral Therapy or Zidovudine Monotherapy: A Meta-Analysis." *Lancet* 362, no. 9396 (2003): 1605-11.

⁷Violari, A., M. Cotton, et al. *Early Antiretroviral*

Therapy and Mortality Among HIV-Infected Infants. *N Engl J Med* 359:2233-44, 2008.

⁸B. J. Eley et al. "Initial Experience of a Public Sector Antiretroviral Treatment Programme for HIV-Infected Children and Their Infected Parents." *S Afr Med J* 94, no. 8 (2004): 643-6.

⁹UNAIDS/WHO, *AIDS Epidemic Update*, December 2009

¹⁰Bradshaw D, Chopra M, Kerber K et al. Every death counts: use of mortality audit data for decision making to save the lives of mothers, babies and children in South Africa. *Lancet* 2008;371:1294-304

¹¹Chopra, Daviaud, Pattinson, Fonn, Lawn. Saving the lives of South Africa's mothers, babies and children: can the health system deliver? *Lancet* 2009;DOI:10.1016/S0140-6736(09)61123-5

¹²WHO, *Mortality Profiles* (Geneva: WHO, 2008). Available online at <http://www.who.int/whosis/mort/profiles/en> (accessed September 12, 2011).

¹³A. Krug, R. C. Pattinson, and D. J. Power. "Why Children Die: An under-5 Health Care Survey in Mafikeng Region." *S Afr Med J* 94, no. 3 (2004): 202-6.

¹⁴WHO, UNICEF and UNAIDS. *Towards Universal Access: Scaling up Priority HIV/AIDS Interventions in the Health Sector*, Progress Report 2010.

¹⁵Address by President Jacob Zuma on the occasion of World AIDS Day, Pretoria Showground, 1 December 2009. <http://www.info.gov.za/speeches/2009/09120112151001.htm> (accessed 12 June 2011)

¹⁶Vasan A, Kenya-Mugisha N, Seung KJ et al. Agreement between physician and non-physician clinicians on starting antiretroviral therapy in rural Uganda. *Human Resources for Health*, 20 August 2009. DOI: 10.1186/1478-4491-7-75.

¹⁷Shumbusho F, van Griensven J, Lowrance D et al. Task shifting for scale up of HIV care: Evaluation of nurse centered antiretroviral treatment at rural health centres in Rwanda. *PLoS Med* 2009;6(10). <http://www.plosmedicine.org/article/info:doi%2F10.1371%2Fjournal.pmed.1000163>

¹⁸Bedelu, Ford N, Hildebrand K, Reuter H. Implementing antiretroviral therapy in rural communities: The Lusikisiki model of decentralized HIV/AIDS care. *J Infect Dis* 2007;196:S464-468

¹⁹Bolton-Moore C, Mubiana-Mbewe M, Cantrell R. Clinical outcomes and CD4 response in children receiving antiretroviral therapy at primary care facilities in Zambia. *JAMA* 2007;298:1888-1899.

²⁰Cohen R, Lynch S, Bygrave H et al. Antiretroviral treatment outcomes from a nurse-driven, community-supported HIV/AIDS treatment programme in rural Lesotho: observational cohort assessment at two years. *J Int AIDS Soc* 2009;12:23 doi:10.1186/1758-2652-12-23

²¹Van Griensven J, De Naeyer L, Uwera J et al. Success with antiretroviral treatment for children in Kigali, Rwanda: experience with health center/nurse-based care. *BMC paediatrics* 2008;8:39 doi:10.1186/1471-2431-8-39

²²Colvin CJ, Fairall L, Lewin S et al. Expanding access to ART in South Africa: The role of nurse-initiated treatment. *SAMJ* 2010;100(4):210-212

²³Horwood C, Vermaak K, Rollins R, et al. Paediatric HIV management at primary care level: an evaluation of the integrated management of childhood illness (IMCI) guidelines for HIV. *BMC Paediatrics* 2009;9:59





Patient-centred care for children with HIV&AIDS

*Susan Isaacs (Operations Manager) & Paul Roux (Consultant Paediatrician)
G26 Paediatric HIV&AIDS Service, Groote Schuur Hospital*

Just being there makes a difference

Families affected by HIV&AIDS should be provided with all the care they need under one roof, as close to their homes as possible. These families have to cope with a serious, chronic illness affecting more than one generation. They face high levels of psychological stress, often in the face of economic deprivation. The G26 Paediatric HIV&AIDS Service at Groote Schuur Hospital began thirteen years ago in an attempt to provide continuity of care for children diagnosed with HIV&AIDS. The clinic has developed a patient management system for chronic disease that contains elements of the primary health care approach. We recognise the importance of teamwork and specialist roles of care-giver, nurse, counsellor, clinician, booking clerk, data capturer and pharmacist.

Individual patients and their care-givers are allocated to specific counsellors and clinicians. Care-givers are offered a broad range of services and support. The Kidzpositive Family Fund, a Non-Governmental Organisation (NGO), registered as a Section 21 Company and Public Benefit Organisation (PBO) raises funds, runs an income generation project and contributes resources to

augment and amplify services provided by the public health care sector at three treatment sites.

It is challenging to provide quality care in the face of high patient volumes. There is a steady turnover of clinicians, nurses and pharmacists, largely because there is no evident career path in HIV&AIDS care for these professionals. Adherence counsellors deal with complex cases and families facing heavy psychological stress, without sufficient training.

The Groote Schuur Hospital medical and nursing administration has been generous in providing space and opportunity to develop the service.

Continuity of care

Each patient has a 'personal' clinician and counsellor. Health care workers keep diaries to record their patients' future visits and accommodate projected leave and study commitments. Booking clerks and nurses direct patients to allocated doctors.

Before the advent of anti-retroviral therapy (ART), women would respond to a diagnosis of HIV infection in their child

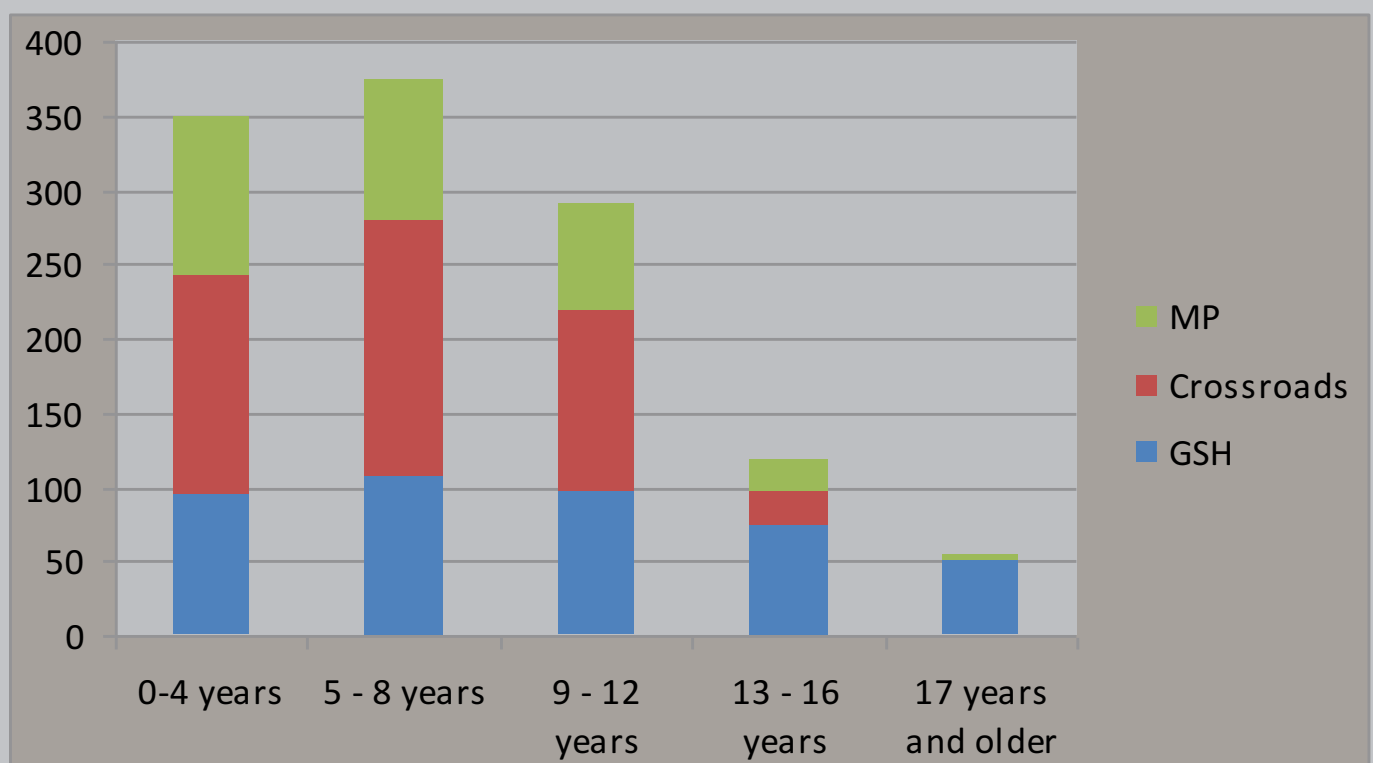
by preparing for loss. Normal patterns of play would alter, and mothers would begin creating distance between themselves and their child. Mothers would revert to normal, closer patterns of play when they began to receive appointments to return to the clinic for future care¹. 'Just being there' can make a real difference.

Comprehensive care

In 1998 the clinic could offer only physical examination, management of intercurrent infections, prescriptions for Co-trimoxazole and multivitamins and access to a support group.

Systematic access to ART became available in May 2002 thanks to a donation from the One to One Children's Fund (www.One2Onekids.org), a charity based in the United Kingdom. By 2004, when government-funded treatment first became available in the public health service, 250 children and 100 mothers were receiving treatment. Currently the service manages 1075 children on anti-retroviral therapy (ART) between Groote Schuur Hospital and two community-based clinics in Crossroads and Mitchell's Plain. Children are doing well

Table 1: Age distribution of children on ART at Mitchell's Plain, Crossroads and Groote Schuur





Our flag on the loom, PGWC bed linen in the background

and growing into adolescence.

The service now provides a family clinic, where mothers and their children can be seen on the same day. These clinics offer counsellor-run support groups for caregivers. Children are entertained in a play area while mothers see their clinician or attend support groups.

Two adolescent clinics cater for young people in junior and senior groups. They offer support groups for adolescent children and for parents of adolescents. Life skills training utilises the Auntie Stella kit (www.tarsc.org). Reproductive health services are available. A part-time clinical psychologist supports adolescents with one-on-one care. A physiotherapist and an occupational therapist are available one clinic day a week and assist in the assessment and management of children with motor and/or developmental delay. Complex cases are referred to a Paediatric

Neurology Service.

Kidzpositive (www.kidzpositive.org), runs an income generation project in the clinic waiting area. Its primary goal is to support food security. Women use hand looms and freehand techniques to complete beadwork at home and bring their products to the clinic for quality screening and counting. They are paid weekly, per completed piece, by electronic transfer of funds into personal bank accounts. Each week, participating women receive parcels of beads, thread and patterns for the following week. This project is offered to all care-givers and supports approximately 130 families most at risk. Each participant can expect additional income of R 600 per month. The project contributes to recovery of a sense of self and self-worth among participating mothers². A DVD illustrating the project can be reached via the Kidzpositive Web site.

Retention in care

Considerable effort is invested – by clerks and counsellors – in following up caregivers and patients who have missed clinic appointments or who have failed to collect repeat prescriptions. Counsellors can do home visits to trace cases. Community-based clinics at Crossroads Community Health Centre and Mitchell's Plain Day Hospital have better retention in care, despite the fact that we fund transport costs for families attending the Groote Schuur service.

Teamwork in the clinic

Teams are made up of equals. Each member contributes specific knowledge, skills and experience to team performance. Our lead nurse is responsible for allocation and use of space and oversight of clinic processes. She schedules weekly team meetings, which are attended by all members and serve as a forum to discuss operations and relationships between members.

Counsellors transmit team plans and decisions through support groups and one-on-one sessions.

Booking clerks and data capturers

Booking clerks operate at point of first contact with patients. They may have to deal with distressed care-givers. The clinic manager and counsellors provide them with support and means to resolve challenges. The efficiency with which clerks perform their tasks benefits the entire clinic. They manage folder flow between hospital records, clinic and pharmacy and make bookings for future clinic visits and specialist appointments outside the clinic.

Data capturers play a central role. They monitor patient visits, alert the clinic to missed appointments and help to identify clients in need of increased counsellor support. Data is channelled to hospital and regional managers and utilised in grant applications and reports to funding agencies.

Nurses

The lead nurse manages the clinic. She oversees the allocation and performance of nursing tasks, utilisation of space, clinic preparation and overall clinic processes. She liaises with hospital and nursing administration. She assists in the resolution of day-to-day conflicts. She faces challenges of team care delivery at outreach sites (see below) and liaises with her opposite numbers at these sites. NGO funding supports additional training and conference attendance.

Counsellors

Counsellors' insights into patient home circumstances are invaluable. Important as they are, counsellors receive only basic levels of training. They are expected to manage very complex cases and carry a heavy burden of work. They are supported by part-time clinical psychologists, particularly in the area of adolescent care. They are supervised by a third psychologist and a social worker. The NGO funds additional support.

An advanced counselling training course - funded by grants to the NGO - is in a planning phase and will have a training faculty made up of nurses, psychologists and members of the Groote Schuur Hospital Infectious Diseases Unit, the HIV Neuropsychiatry service and the Paediatric service.

Clinicians

Clinicians initiate ART and manage follow-up care, adjust ART dosing, treat complications, opportunistic infections, liaise with physiotherapist and occupational therapist and arrange specialist referrals. Children requiring hospitalization have direct access to paediatric beds from clinics and as 'walk-in' cases at all hours. An experienced Medical Officer supervises liaison between ambulatory and in-patient care.

Pharmacists

The clinic has had the benefit of assistant pharmacists dedicated to the ART programme and funded by the NGO. Liaison with the hospital pharmacy provides an early warning system which identifies patients who have not collected repeat prescriptions and are at risk of non-adherence and loss to follow-up.

Community clinics

Our clinic team travels to two 'outreach' clinics each week. It is challenging to introduce a patient-centred ethos into extremely busy, over-crowded community venues. It takes time and effort to show that the primary health care approach, teamwork and attention to detail can add efficiency and reduce work. The visiting team must respect the autonomy and territory of the host venue.

Further benefits from the NGO

Besides running the income generation project, Kidzpositive also provides bus and taxi fares for caregivers and children attending the Groote Schuur Hospital clinic and an 'emergency fund' for families in distress (as a result of flooding, fire, other disasters).

The NGO has obtained funds through grants from international donors for projects including the development of the adolescent service, additional clinic furniture, IT resources, income generation projects at other sites, a gardening project for teenagers, publication of training booklets and development of the training programme for community health workers and our counsellors.

The NGO pays salaries of an additional Medical Officer, locum clinicians, child care workers in our play area, part-time clinical psychologists, an occupational therapist and a physiotherapist.

Acknowledgements

We thank Sidaction, the ANOVA Health Institute, PEPFAR/USAID, the One to One Children's Fund, Paediatric AIDS treatment for Africa (PATA) and the Claremont Rotary Club for support.

References

1. Ramugondo E. L. *Play and playfulness: Children living with HIV&AIDS* (pp 171 - 185). *Transformation Through Occupation: Human Occupation in Context*, Watson and Swartz (Eds). Whurr Publishers Ltd, London
2. Fane, T., Ramugondo, E., Leshoele, M., Coker, T. (2010). *The Experience of beading by women living with HIV&AIDS within the "Kidzpositive Family Fund" Non-Profit Organisation*. *South African Journal of Occupational Therapy*. Vol 40, number 2, July 2010

®

PATIENT
centred care
makes a
difference



Lipodystrophy in children a case report

*Dr Lee Fairlie, Paediatrician Head Paediatric Technical Team WvHI
(Wits Institute for Sexual and Reproductive Health, HIV and Related Diseases)*

The lipodystrophy syndrome associated with antiretroviral treatment (ART) for HIV infection has been the subject of intense research in recent years. It has a significant adverse effect on quality of life and the associated metabolic changes may threaten long-term survival.

Sipho is an 11 year 7 month old boy who currently attends an HIV clinic in Soweto Johannesburg.

Sipho was diagnosed HIV positive in April 2007 at the age of 7 years and 4 months when he was admitted to hospital with a severe pneumonia requiring hospitalization and treatment included oxygen and intravenous antibiotics.

He remained in hospital for a week. Sipho had no TB contacts at the time and his TB investigations were negative. Clinically he was underweight - his weight was 17 kg plotting at 74% expected weight for age. He was also stunted.

Sipho had generalized lymphadenopathy, no clubbing, a clinical right lower lobe pneumonia, and hepatosplenomegally.

Neurological examination was normal. Sipho was doing well at school and passing all subjects.

Blood results:
Sipho's CD4 count was 120 (8%) in April 2007.

Sipho's full blood count and ALT was normal before his ART was started.

Initiation of ART

When Sipho was discharged from hospital he was referred to the HIV clinic where he was started on ART two weeks after discharge.

He was started on stavudine, lamivudine and efavirenz according to the guidelines at the time.

Onset of fat redistribution syndrome

At his last visit in October, Sipho's mother started to complain that he seemed to be losing weight especially on his arms and legs, and his "veins were popping out" on his arms. His mother thought that his abdomen seemed a bit fatter. Sipho had a good appetite and was eating well. There was no food insecurity at home.

Sipho had no other concerning symptoms: he wasn't coughing, had no

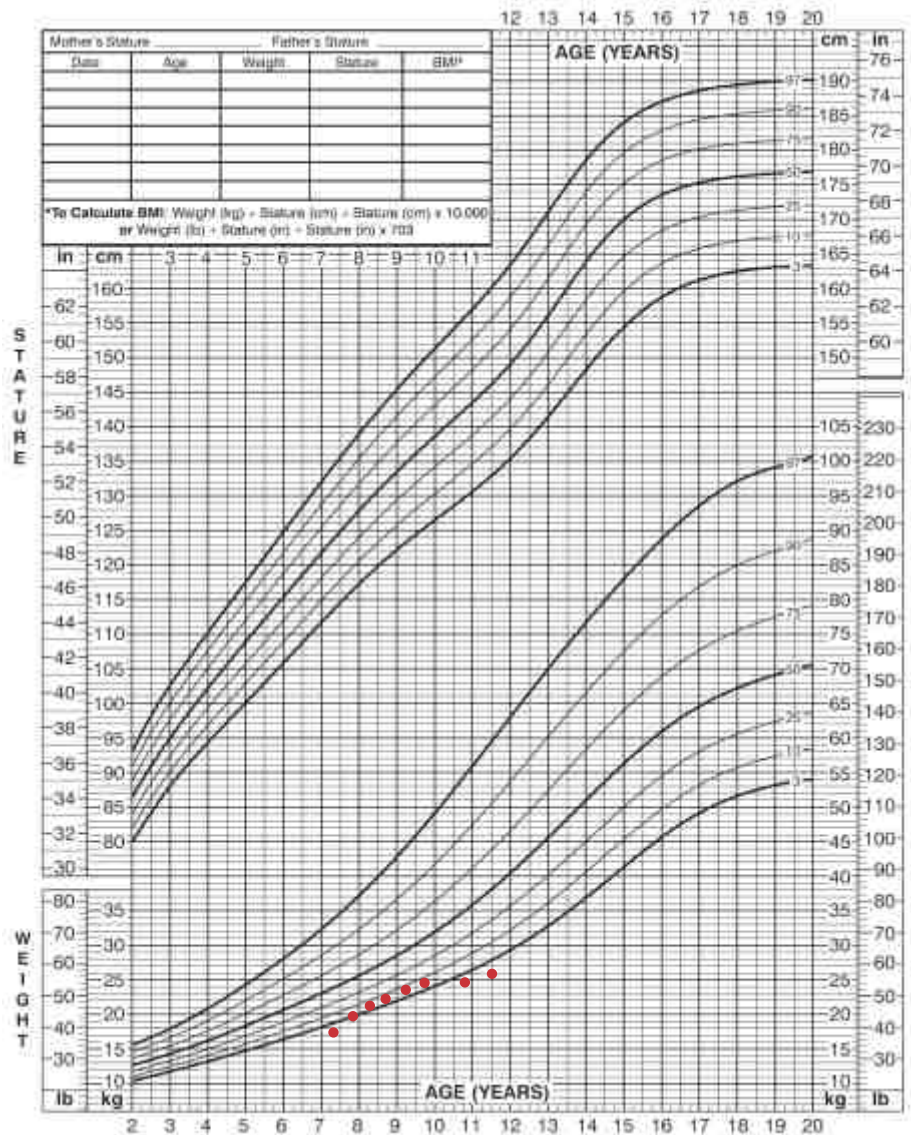


Table 1 Sipho's Response to ART

	October 2007	April 2008	October 2008	April 2009	October 2009	October 2010
Cd4 count	240	360	420	500	525	560
Cd4 Percentage	20	22	24	25	25	26
HIV Viral load	<25	<25	<25	<25	<25	<25
TG/Chol	Normal		Normal	Normal	Normal	Normal
Weight (kg)	20	22	23	23.5	24	24.5



A picture of Siphio is provided in figure 1.

Siphio at the clinic

night sweats, no diarrhea and there were no known TB contacts at home. Siphio was also doing very well at school and had plenty of energy at school and at home.

On examination it was noted that Siphio had not gained weight for a while when we looked back at his past few months of clinic visits and was starting to fall below the 3rd and 10th percentile for age.

He had some facial wasting and his arms and legs were very thin with prominent cubital fossae veins and subcutaneous tissue loss over arm and leg muscles with prominence of biceps, forearm muscles and calf muscles. There was also increased fat deposition around his breasts although there was no gynaecomastia clinically. There was also some abdominal fat deposition.

The rest of his examination findings were normal.

Diagnosis of fat distribution syndrome

Siphio was diagnosed with FAT REDISTRIBUTION SYNDROME. Fat redistribution syndrome which includes lipatrophy and lipodystrophy occurs in up to 25 % percent of children on ART. Fat redistribution syndrome also occurs

commonly in adults. The symptoms of this syndrome are presented in the accompanying box.

Fat redistribution syndrome presents with the following symptoms:

- There is fat loss and/or fat accumulation in distinct regions of the body:
- Fat loss from limbs, buttocks and face
- Buttock wasting
- Increased fat around abdomen
- Breast hypertrophy
- Buffalo hump (less common in children)

Fat redistribution syndrome may also be associated with metabolic syndrome (insulin resistance, hyperglycaemia, hypertriglyceridaemia, hypercholesterolaemia and low HDL levels). These individuals are at risk of type 1 diabetes mellitus and coronary artery disease. Lactic acidosis, pancreatitis, hepatic steatosis, peripheral neuropathy may also occur but fortunately these conditions are rare in children.

The syndrome usually occurs in patients who have been on long-term ART and is

more common in individuals taking NRTI's such as stavudine and didanosine or protease inhibitors.

Most of the time in our setting the diagnosis of fat redistribution syndrome is made clinically and it may be helpful to ask the caregiver, who will often notice the changes in a child's appearance, for comparative photographs. When there is access to more sophisticated diagnostic tools the measures referred to in table 2 can be used to assist in making the diagnosis:

Management of fat redistribution syndrome

- At the first indication of lipodystrophy, stavudine, didanosine or zidovudine should be changed to abacavir to prevent further irreversible lipodystrophy changes. There is little possibility for reversibility but usually no progression once drugs are switched so it is best to switch the offending drug/s EARLY.
- There are no established methods for treating lipodystrophy.
- Encourage exercise to reduce fat accumulation.
- Some patients improve if switched from a protease inhibitor to an NNRTI.
- Statins and or fibrates are effective at lowering cholesterol and triglyceride

Table 2: Diagnosis of fat redistribution syndrome

Anthropometrical measures	Radiological	Other
<ul style="list-style-type: none"> • Regular weight and BMI • Mid arm circumference • Triceps skin fold • Abdominal girth 	<ul style="list-style-type: none"> • CT abdomen • MRI • DEXA scans 	<ul style="list-style-type: none"> • Comparative photographs • Caregiver may notice a change in the child's appearance

levels.

- Insulin resistance can be improved with anti-diabetic agents.
- A single drug substitution of stavudine or didanosine for abacavir can be made if the **HIV viral load is suppressed** in children. It is always important to check that a child is virally suppressed before only one drug is substituted as failing to do so can risk losing the other ART in the regimen as a result of resistance developing.
- In adults or older children stavudine or didanosine can be substituted for tenofovir if the **HIV viral load is suppressed**.

REFERENCES:

Department of Health South Africa. Guidelines for the Management of HIV in Children. Second Edition 2010.

LEARNING POINTS

- Fat redistribution syndrome is usually diagnosed clinically and a high index of suspicion is required.
- The usual causative agents are stavudine, didanosine and to a lesser extent, zidovudine.
- As soon as the diagnosis is suspected, and if the child has been virologically suppressed in the previous 6 months, with no concerns about adherence, the offending drugs must be switched to either abacavir in younger children or TDF in older children or adolescents.
- The earlier the switch the better as there is little reversibility once lipodystrophy has occurred.

Sánchez Torres AM, Munoz Muniz R, Madero R, Borque C, García-Miguel MJ, De José Gómez MI. Prevalence of fat redistribution and metabolic disorders in human immunodeficiency virus-infected children. *Eur J Pediatr.* 2005 May;164(5):271-6. Epub 2005 Jan 14.



Lipodystrophy is usually irreversible but further development of lipodystrophy can be prevented

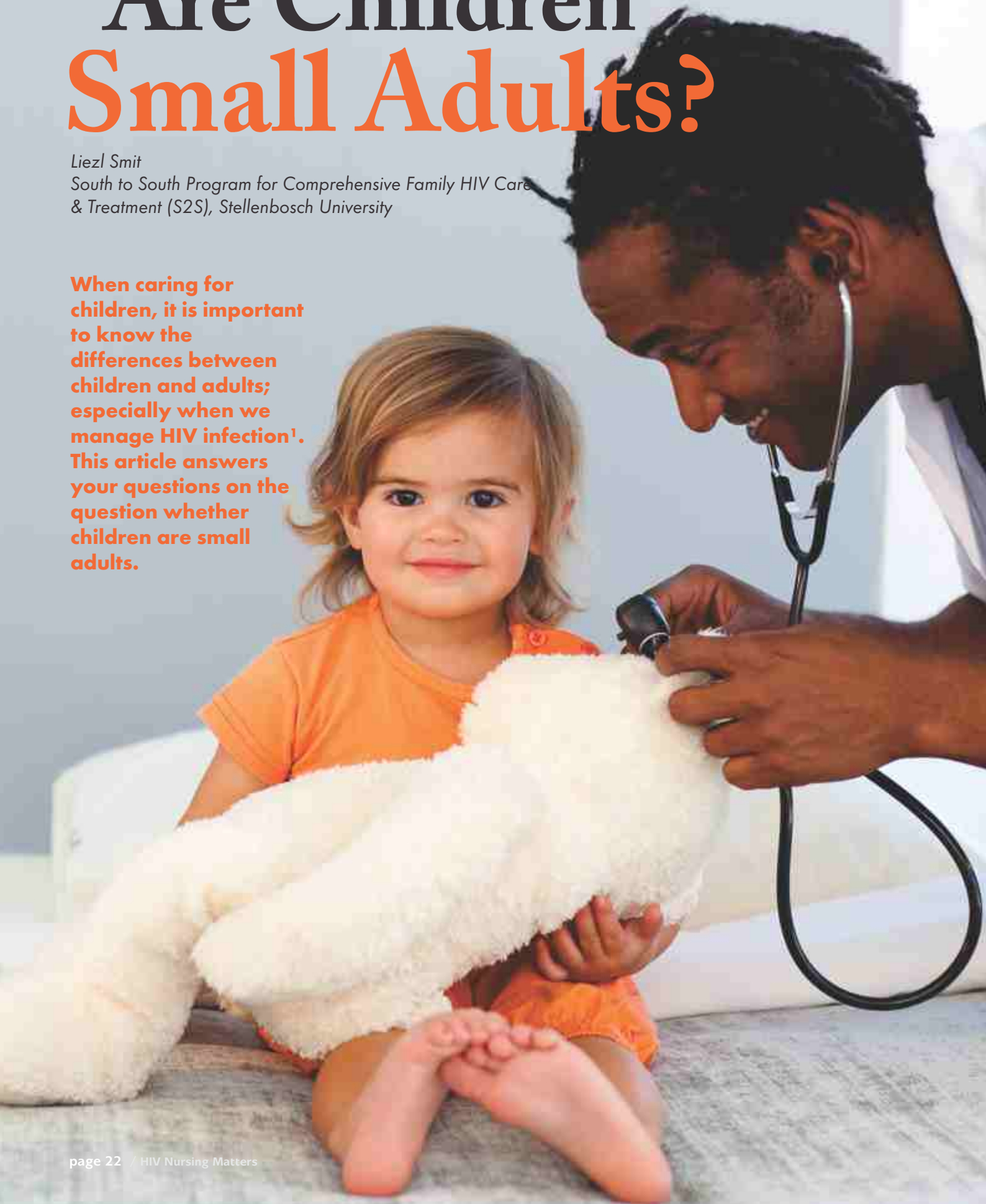


Are Children Small Adults?

Liezl Smit

South to South Program for Comprehensive Family HIV Care
& Treatment (S2S), Stellenbosch University

When caring for children, it is important to know the differences between children and adults; especially when we manage HIV infection¹. This article answers your questions on the question whether children are small adults.



1. Why do paediatricians always talk about the importance of 'growth and development' in children?

Neurodevelopment as well as growth should be monitored routinely in all children, but especially in children exposed to or infected with HIV.

Growth is the 'work' of the child. Growth is the best general indicator of the health of any child and regular growth measurements helps with early detection of malnutrition, failure to thrive and other illnesses at which point the treatment intervention required is simpler.

Growth failure can occur throughout the course of HIV disease. It can be the primary manifestation of HIV disease in the HIV-exposed infant. It is a very sensitive indicator of HIV disease progression in children indicating the need to initiate ART and it can be an indication of treatment failure.

Adults usually lose weight when ill; whereas children may just fail to gain weight. Failure to thrive will only be seen if the weight is plotted on the child's growth chart.

Furthermore, you need the child's weight to calculate drug dosages at every visit!

One of the first and most important clinical features of HIV infection in children is a delay in neurodevelopmental milestones, often accompanied by a slowing of head growth. This may be the first sign of HIV encephalopathy, an AIDS defining illness. Developmental delay caused by HIV may not be reversible even if ART is started.

If you have not assessed the growth and development of a child during the health visit, you have not assessed the child.

2. How do children become infected with HIV?

The majority of children (>95%) gets HIV from their mothers (vertical transmission), either during pregnancy, labour & delivery or breastfeeding. HIV in children is thus mostly a preventable disease and with the current available interventions to prevent mother to child transmission (PMTCT) of HIV, < 2% of children should be infected this way.

Other causes of infection include unprotected sexual contact (horizontal transmission): sexual abuse or consensual sex in adolescents, wet-nursing with HIV contaminated breast milk, blood transfusion with HIV infected blood, health care workers using contaminated needles, syringes or surgical instruments, or using HIV contaminated needles or blades in traditional rituals.

In Africa, most adults and adolescents are infected through heterosexual intercourse.

3. How do we diagnose HIV infection in children?

Most HIV infected infants appear normal and healthy at birth; a clinical examination cannot be used to determine HIV infection in newborns. The clinical signs of HIV often appear at age three to six months. In any child with clinical symptoms or signs suggestive of HIV, counseling and HIV testing should be offered.

HIV antibodies are made in response to HIV infection. All HIV exposed infants are born with maternal HIV antibodies as it cross the placenta. These maternal antibodies wane over time and disappear at around 18 months of age. The rapid antibody tests detect whether HIV antibodies are present, but do not differentiate between maternal and infant antibodies. All HIV exposed infants (both HIV infected and HIV

uninfected) may have a positive rapid test up to 18 months of age. In children older than 18 months, a positive antibody test means that the child is producing his/her own antibodies and is HIV infected.

The only reliable method of determining HIV infection in infants less than 18 months is to use specialized virologic tests, polymerase chain reaction (PCR), looking for the viral genetic material. The first PCR test is performed 4-6 weeks after delivery.

Exposure to HIV and risk for acquiring infection continues throughout the breastfeeding period and a PCR test needs to be repeated 6 weeks post weaning off breast milk in children less than 18 months of age.

4. Why do we do the PCR test at 6 weeks?

The window period for the PCR test is 6 weeks. A positive PCR test before six weeks will confirm HIV infection in the majority of infants infected during pregnancy, labour and delivery and the early postpartum period. A negative test cannot reliably exclude infection.

Most infants have their first visit for immunization and growth monitoring at 6 weeks. This allows for an opportunity to identify HIV infected infants as early as possible and refer them for treatment.

5. How does HIV disease progression in children differ from adults?

Following primary HIV infection, there is a latent phase before chronic symptomatic HIV illness develops. During this latent phase there may be no clinical signs at all or only persistent, painless generalised lymphadenopathy.

In adults this latent phase usually lasts five to ten years. In children, this is much shorter owing to their

immature immune system. Children who are infected before, during or soon after delivery usually progress fast (remember, these are the infants with positive 6 week PCR!) and become symptomatic by three to six months of age. Without appropriate treatment, half of these infants will be dead by the age of two.

Children who are infected later, usually via breast milk, tend to progress much slower. Without appropriate treatment most will die by five years, but some may survive beyond ten years of age.

6. What are the common clinical presentations of HIV infection in children?

Chronic HIV infection can present with a very wide range of clinical symptoms and signs. Common ways that HIV infection can present includes:

- Weight loss or failure to thrive
- Severe or persistent oral thrush beyond the first two months of life
- Enlarged lymph nodes, liver, spleen or parotid glands
- Severe rash
- Serious, repeated or chronic bacterial infections such as pneumonia
- Severe forms of common viral infections which often respond slowly to treatment such as severe oral herpes
- Chronic diarrhoea
- Tuberculosis
- Infections which do not usually affect children with a healthy immune system, such as oesophageal candidiasis
- Delayed developmental milestones

7. Is the WHO clinical staging in children the same as in adults?

Yes. The WHO clinical criteria divide HIV disease in 4 stages: an asymptomatic stage (stage 1), followed by three symptomatic stages (stage 2, 3 and 4). As the HIV disease progresses and the

illness becomes more severe, the clinical stages progresses from 2 to 4.

It is important to do clinical staging of children infected with HIV at every visit. Clinical staging allows health care providers to monitor disease progression, assess for ART eligibility and assess response to ART (treatment failure).

8. Why do we use CD4 in children?

In addition to clinical staging of HIV infection, patients should also be staged immunologically. The number of CD4 cells is a direct measure of the degree of immune suppression and the associated risk of developing opportunistic infections.

The CD4 count is the number of CD4 cells in one thousandth of a milliliter of serum. In normal healthy adults who are HIV negative, the CD4 count is above 500 $\mu\text{l/ml}$. In children the normal range is higher, especially in younger children who have an immature immune system. As the CD4 count varies according to the child's age, it is preferable to use the CD4 rather than the absolute CD4 count in children younger than 5 years of age. The CD4 is the percent of lymphocytes in the blood that are CD4 cells.

9. How do we interpret CD4 in children?

In normal healthy children, more than 25% of the lymphocytes in their blood should be CD4 cells. If the CD4 is less than 25%, the immune system is suppressed. A CD4 between 15 and 24 indicates moderate immune suppression, with a CD4 less than 15 indicating severe immune suppression.

10. Do we need a different approach to adherence and psychosocial support in children?

Children should not be seen separately from their families or

communities. They are dependent on their caregivers for adherence to treatment and health visits. Children's needs changes as they develop and grow; the multidisciplinary team must be aware of this and adapt the treatment and care plan accordingly. Remember, babies can't take tablets, and adolescents won't!

It is important for a child to know his/her HIV status and/or that of a family member. Open communication about the infection or illness will allow the child to express his/her fears, obtain support, understand the infection, and participate in finding ways of taking treatment regularly. Of course, disclosure should take family, community, legal and child right issues into consideration, should occur when age-appropriate, and should be conveyed with appropriate language and terms.

Reference

Prof Dave Woods and Prof Brian Eley. Childhood HIV - What health professionals need to know. EBW healthcare series. www.ebwhealthcare.com



WITHOUT
treatment, most
children will die
by five years

Win a bursary for the CMART programme in Stellenbosch

The Southern African HIV Clinicians Society and Stellenbosch University's Nursing Division are pleased to offer a ONE bursary to a Society member to attend Stellenbosch University's certificate in the Comprehensive Management of Patients on Antiretroviral and Tuberculosis Treatment (CMART). The course will commence in February 2012; dates are not yet finalised.

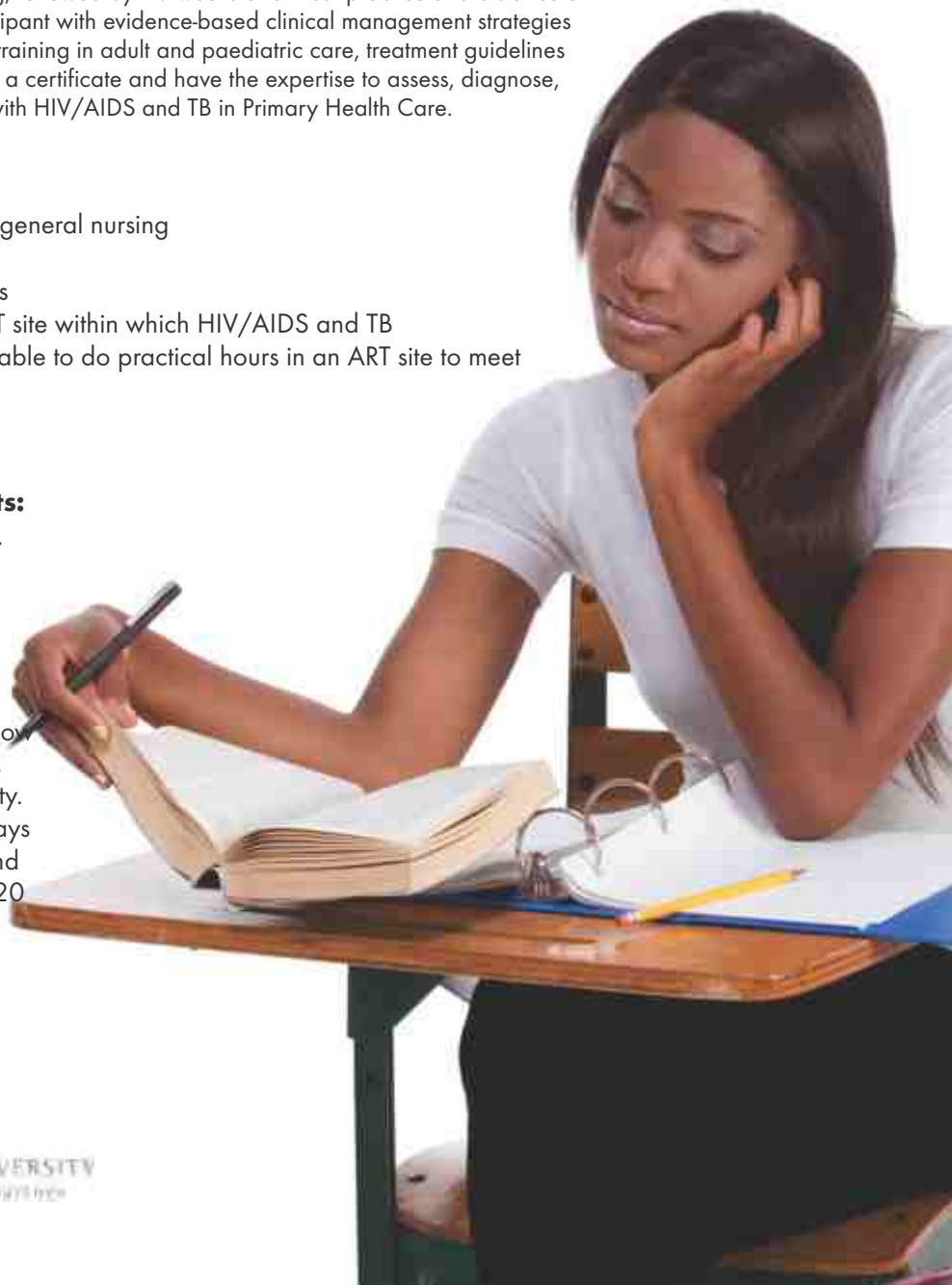
The course consists of a 5 day initial workshop at Stellenbosch University's Tygerberg campus in Cape Town that includes specialized skills training, followed by 20 weeks of clinical practice and distance e-learning. CMART provides the nurse participant with evidence-based clinical management strategies for HIV/AIDS and TB. The course includes training in adult and paediatric care, treatment guidelines and PMTCT. Successful graduates will earn a certificate and have the expertise to assess, diagnose, prescribe medication and manage clients with HIV/AIDS and TB in Primary Health Care.

Bursary eligibility requirements:

- A professional degree or diploma in general nursing
- Current registration with SANC
- Computer literacy and internet access
- Practicing in an ART site or future ART site within which HIV/AIDS and TB management is/will be a service, or able to do practical hours in an ART site to meet logbook requirements
- PALSA Plus and IMCI certificate

Bursary application requirements:

- Completed CMART application form.
- Completed bursary application form, which includes:
 - An overview of your current position and job responsibilities.
 - A motivation outlining both need and desire for a bursary. Please include how enrolment in CMART will benefit you, your organisation and your community.
- Letter from supervisor approving 5 days leave for you to attend the course, and commitment to support you over the 20 week distance learning period.
- Two professional references.



UNIVERSITEIT-STELLENBOSCH-UNIVERSITY
2011

Application process:

Application forms are available online at www.sahivsoc.org and must be submitted by email to sahivsoc@sahivsoc.org

Closing date:

1 November 2011

PAEDIATRIC DISCLOSURE LEGAL AND ETHICAL IMPLICATIONS FOR NURSES AND HEALTHCARE WORKERS

Janine Clayton and Doranne McDonald

South to South Program for Comprehensive Family HIV Care & Treatment



Paediatric disclosure requires healthcare workers to adequately prepare children for the process of disclosure. Many healthcare workers express the need for assistance and support to do this.

As HIV has moved from an acute, fatal disease, to one that can be managed with medication, an increasing amount of children will grow up living with HIV as a chronic disease. It is, therefore, crucial for children to learn about their disease in a manner in which they can understand, so that they can take an active role in their treatment and care.

The process of paediatric disclosure, therefore, is an extremely important component of the care of children living with HIV. Many nurses and healthcare workers in South Africa today are confronted with HIV disclosure, but few feel adequately skilled and equipped to deal with the process, as well as the legal framework that governs it. Feedback from healthcare workers in the HIV field shows that assistance and support are needed to navigate the disclosure process with children and their caregivers successfully.

HEALTHCARE WORKERS BARRIERS TO DISCLOSURE

Healthcare workers may often find it difficult to discuss HIV infection and disclosure with caregivers and their children. Some of the barriers identified in working with issues regarding paediatric disclosure included:

- Similarly to caregivers, not knowing where or when to start
- Unsure about their role in initiating and completing the process
- Concerned that disclosure will be harmful to the child
- Differences in opinion about disclosure between healthcare workers, the caregiver, or amongst the multidisciplinary team. It can be challenging when the healthcare worker thinks that the child needs to understand his or her HIV diagnosis and the caregiver does not share this understanding, and does not want to proceed with disclosure

Paediatric disclosure demands that healthcare workers, more specifically nurses, and caregivers adequately prepare children for the process of disclosure. Before this takes place, however, it is essential for the multidisciplinary team of healthcare workers to ensure that caregivers are similarly prepared for this task. To improve the chances for successful disclosure to children, the team of healthcare workers should ensure that the caregiver is able to cope with disclosure to the child, assist the caregiver in preparing for the process of disclosure, and help the caregiver to convey a sense of hope and optimism to the child. Often this means that the caregiver's own needs and challenges regarding his or her own issues of disclosure might need to be addressed. In order to be more effective in facilitating the process of paediatric disclosure it is useful for us to understand some of the barriers that caregivers face in terms of disclosure.

CAREGIVER BARRIERS TO DISCLOSURE

Disclosure of HIV status to children can be an extremely difficult topic for caregivers to broach with their children. They may not want to disclose a child's diagnosis for a number of reasons, and could be as follows:

- The caregiver thinks the topic is too complicated for the child to understand, or that the child is too young
- Due to tradition and culture, the caregiver is not used to discuss important issues with the child, and may think that it is inappropriate to do so
- The caregiver does not know where to start, or how to anticipate or respond to children's questions. He or she may lack support in the home and community, and have no access to a trained healthcare worker to help prepare for disclosure
- The caregiver may lack knowledge and/or comfort with the facts around HIV
- The caregiver fears causing psychological harm to the child
- The caregiver wants to protect the child and/or family from stigma, discrimination, and rejection
- The caregiver may be experiencing parental guilt regarding transmission, or fears the child will accidentally disclose his or her status, or the parent's HIV status
- The caregiver may have difficulty coping with his/her own illness, or that of loved ones
- The caregiver is unrelated to the child and/or the child is an orphan.

Despite these barriers to disclosure, there are lots of good reasons for wanting to talk to children about their HIV status. It is part of their lives, and preparing them to know about their status, is part of preparing them for life. It is also the child's right to know. The Children's Act of South Africa supports and acknowledges that children over

the age of 12 years may be accorded more rights to knowledge about their health, or consent to treatment.

Further advantages of children knowing their HIV status is summarised below.

ADVANTAGES OF CHILDREN KNOWING THEIR HIV STATUS

- Children who know their HIV status can take an active role in their care and treatment plan, and when old enough, can take steps to live positively, and prevent new infections
- When children learn about their status directly from their caregivers, it can provide comfort and reassurance. Keeping secrets is hard. Too often, children overhear healthcare workers and caregivers talking about their health as if they are not in the room. Efforts should be made, when developmentally appropriate, to include children in discussions about their health
- Children often ask to know what is wrong. They are observant, smart, and curious. They often know much more than adults realize
- Children may already suspect their HIV status, but are keeping it a secret, or waiting for an adult to tell them
- Children may have fears about their HIV status, especially if one or both of their parents have died
- Children, who have not been disclosed to may develop their own views about their illness, feel isolated from support, learn their HIV status by mistake, or present with behavioural problems
- Children have a right to know about their body and health, when they are able to understand
- Children can learn to protect others when they know their status.

The process of disclosure

Current trends dictate that disclosure

should be an on-going process that takes into consideration the readiness of the caregiver and family, the developmental level of the child, as well as input and guidance from the healthcare worker, as appropriate, and needed. The child is, therefore, integral to the disclosure process, and is now included. This is a significant contrast to past practices, where the issue was discussed with caregivers only, and the child was ignored, or dismissed from the process. Disclosure should not be seen as a "once-off" event, but rather a process starting before the child is even aware of the term "HIV", and continues throughout his/her life, even after full disclosure of status has occurred.

The disclosure support needs of children and families vary, depending on:

- Age at diagnosis
- The health status of the child (For example, symptomatic children, particularly those requiring hospitalization, should be informed of their status sooner, as the likelihood of children mistakenly learning about their status in hospital, is high)
- How the HIV was transmitted.

The terms "partial disclosure" and "full disclosure" are used in to distinguish between varying levels of information-sharing practices among persons living with HIV. Amongst children, partial disclosure refers to telling a child only some information about his or her illness. It serves as a means of protecting the child and family from inappropriate disclosure, and the possible effects of stigma and discrimination. Full disclosure means naming, and giving more HIV-related details to the child. Families and caregivers must decide at what point full disclosure is necessary. It is generally recommended that children should be fully disclosed to when they are developmentally ready to understand the information.

Many healthcare workers and caregivers grapple with the very real dilemma, however, of when the correct age is for paediatric disclosure. Although not ignored, the focus has increasingly shifted from "when", to "how" to disclose. This has given rise, therefore, to the developmental approach to disclosure, which, interestingly, corresponds with healthcare workers experiences when

having dealt with paediatric disclosure, informally, in the last few years.

WHAT DO I TELL MY CHILD?

Important tips for healthcare workers when assisting caregivers with the process of disclosure: Most importantly, you need to help your child make sense of what is happening to them. You do not have to tell your child everything at once. Telling your child about HIV can occur over time, step by step. These are some general guidelines:

- Be honest.
- Use words that they will understand.
- Be prepared to answer questions.
- Try not to dwell on the negative things.
- Let them know who they can talk to about HIV and where to get support.
- Use their experience of illness as a starting point for talking.
- Find out if they already know about HIV from school, books and television.

Talking about HIV will not happen on a daily basis, but you need to have more than one talk about it. It is important to let your child know that illness is **part** of their life, not all of it. Exactly what you say depends on a lot of things, including:

- The age of your child.
- Their level of maturity.
- What they already know.
- How much they know about HIV, perhaps what they've learned from school.
- Their personality.
- What illnesses they've had.
- Whether they're on treatment or not.
- The health of other people in the family.
- Events like moving house, changing schools, exams etc.

Adapted from: *Where do I start? Talking to children with HIV about their illness*, Paediatric HIV Team, Department of Infectious Diseases, St George's Hospital, London

In the developmental approach, decisions about when to start talking to a child about their HIV status is determined by the readiness of their caregiver, as well as the developmental age of the child. This will obviously differ for every child, therefore, to provide a specific age for disclosure, is no longer appropriate. An overview and understanding of childhood development, however, is crucial for all healthcare workers to effectively support caregivers through the disclosure process.

Legal framework governing paediatric disclosure in South Africa

Healthcare workers are governed by The Children's Act of South Africa (2005) in all interactions with children. The Children's Act states that a child may consent independently to HIV testing, if he or she is 12 years or older, or under the age of 12 years, and of "sufficient" maturity to understand the benefits, risks, and social implications of such a test.

A child is considered to be "sufficiently mature" if he or she can demonstrate that he or she understands information on HIV testing, and can act in accordance with that understanding. The following factors should be considered when assessing a child's maturity:

- Age.
The older the child the more likely it is that he or she will have sufficient maturity.
- Knowledge.
Children with knowledge of HIV and its implications are more likely to understand its consequences.
- Views.
Children who are able to articulate their views on HIV testing, and whether it is in their best interests are likely to meet the maturity requirements.
- Personal circumstances.
An assessment of the child's personal situation, and his or her motivations for HIV testing, may help in assessing their maturity.

Support

In some cases, however, it may not be possible, or acceptable, for the mother or primary caregiver to be the person who engages in the disclosure process with the child. This may be due to a

variety of reasons. For example, it may be culturally inappropriate to do so, or the mother or caregiver may be ill, dead, or unable to start the discussions. In such cases, it is helpful for the healthcare worker to initiate discussions with the caregiver about who would be most appropriate to begin discussions of disclosure with the child. The healthcare worker should be open to a range of possibilities, for example, aunt, grandmother, or trusted church or community leader, and discuss with the caregiver the most appropriate means of disclosing to the child and family.

One of the best ways to support a child, who knows his /her HIV status, is by giving them the chance to ask questions if they need to, and to allow them to talk about their concerns and worries. Talking to their caregivers about their feelings regarding their HIV status may be important to children; however, children sometimes need to talk to people who are not close to them. They may be reluctant to talk to their caregivers for fear of upsetting them, and it can be easier for them, therefore, to talk to someone else, for example, a healthcare worker. It is important that children know who they can talk to, so it is useful to inform them of available support in this regard. Some of the people who they may speak to are:

- Close relatives
- Close friends
- Healthcare professionals (nurses, doctors, psychologists, social workers)
- Religious leaders
- Community leaders
- Support groups.

Conclusion

Paediatric disclosure is a complex process, but yet a very necessary reality, faced by healthcare workers, and caregivers on an ever-increasing basis. Overburdened and inadequately resourced healthcare systems, coupled with unskilled healthcare workers and caregivers, has made the process seem intimidating. Once healthcare workers gain the necessary skills and confidence to address disclosure with caregivers, and, thereby, children infected with HIV, the benefits are pronounced, as adherence and patient well-being increase dramatically.

Case Study: Nomsa

Nomsa is a 5-year old girl who lives with her grandmother, Mpho. Before the discussion regarding her health, Nomsa had been refusing to take her medicine.

Mpho had not told Nomsa why she must take the medicine, as she thought that Nomsa was too young to understand such things. After being told about needing medicine to be healthy, Nomsa still refused to take her medication, and she has now begun asking her grandmother more questions about her illness.

What was the impact of disclosure? What continuing needs, including support, do Nomsa and her family have? What are the legal and ethical considerations that we need to be aware of?

Discussion

Key issues that should be considered in the case study are as follows:

- The impact of disclosure is Nomsa's new interest in learning more about her illness, though it has not affected her willingness to take her medication.
- Nomsa is still very young, and while discussions of her illness have begun, she still does not understand why she needs to take the bad-tasting medication.
- The primary concern here is to help Nomsa's grandmother, Mpho, problem-solve as to how to get Nomsa to take her medication, by disguising the taste somehow.
- Another important need is to begin to answer Nomsa's questions about her illness. The healthcare worker should guide Mpho on what kind of information can be passed on, for example, that the sickness is inside her, and that medication, and visits to the clinic help to keep her healthy.
- Mpho may also benefit from being connected with a support group of other caregivers, or if this is not available, other

caregivers who may have experienced the same challenges that she is now facing.

**IMPORTANT CONTACTS FOR
CHILDREN AND ADULTS
INFECTED AND AFFECTED BY
HIV/AIDS
AIDS HELPLINE**

For all problems related to HIV/AIDS
0800 012 322
www.aids helpline.org.za

**LOVE LIFE CALL CENTRE:
THETHA JUNCTION**

For information about lifestyle matters focusing on adolescents.
0800 121 900
www.lovelife.org.za

CHILDLINE

For all children's issues.
0800 055 555
www.lifeline.org.za

**SOUTH AFRICAN HUMAN
RIGHTS COMMISSION –
CHILDREN'S DESK**

For information on children's rights as well as assistance in getting support in pertaining legal aspects/issues
011-8773600
www.sahrc.org.za

HOPE WORLD WIDE

Countrywide programmes to help children and young people to live with HIV or AIDS.

References

Department of Health, Republic of South Africa. *HIV Counselling and Testing Policy Guidelines*. March 2010.

Disclosure Process for Children and Adolescents Living With HIV. Facilitator's Manual. South to South Partnership for Comprehensive Family HIV Care and Treatment Programme, ICAP & FXB. USAID-funded. 2010.

Waugh S, Donaghy S, Faulknull, Baverstock J. (2003), "Where do I start?" *Talking to children with HIV about their illness*: London, United Kingdom.

Republic of South Africa. (2006). *Children's Act 2005*. Government Gazette. Vol. 92, No. 28944. Retrieved from <http://www.info.gov.za/view/DownloadFileAction?id=67892>.



Nurse-led services for peads

South African health services are dependent on nurse-led services to address the burden of HIV&AIDS disease in our country. This article tells the story of one of our professional nurses, Boy Mahlangu, who is making a difference in the care of children living with HIV and is highly regarded by his colleagues.



Professional Nurse Boy Mahlangu works at the Vosloorus Primary Healthcare Clinic in Gauteng where both adults and children are treated for HIV & AIDS related conditions. He works in the CCMT section at the clinic where he enjoys working with children. He started his career as a student nurse at the Lebone Nursing College where he completed his Diploma in Nursing Science and Midwifery. During this period he did the practical component of his training at the Tembisa Hospital. He continued to improve his knowledge and skills by completing a Degree in Primary Healthcare at the Johannesburg

University during which he mostly worked at the Johannesburg hospital. At the University of Stellenbosch he completed a certificate in HIV and TB care with his practical mostly completed at the Helen Joseph hospital.

Nurses and paediatric care

Most nurses do not want to deal with kids "also myself in 2006 when I started working here" says Boy Mahlangu. But since then he has come to enjoy working with the children. He started by doing VCT for paediatrics and was encouraged by Dr McDonald who saw his interest in caring for children. Dr McDonald mentored him by providing him with books and other information to read "getting me involved in interesting cases and later giving me cases to manage" he says.

Challenges in the workplace

When asked what the challenges are he experienced in his workplace, Boy immediately identified taking blood from children for laboratory tests as the biggest challenge for all practitioners. Both nurses and doctors are not used to taking blood from children. This is a skill that Boy Mahlangu has mastered and he does the bloods most of the time. If he is not on duty, it is often said that patients should come back the next day for bloods, but they are then rather sent to the hospital to get their blood taken. The nearest hospital is the Natalspruit hospital. The challenge here is that

patients may not go to the hospital or may not come back the next day, so it is better to do the bloods on the same day that they visit the clinic.

The second challenge is medication. The medication prescribed and administered for children are very different from that of adults. This was a particularly big challenge in the time before revised HIV&AIDS guidelines (April 2010) and those by Right-to-Care, were made available to guide practitioners in their clinical practice. At the clinic pharmacist assistants issue the prescribed medication for children, but the nurse still has to make sure that the parents are advised on how to administer the medications, especially if it is something that has to be mixed with water. "There are often conditions that we as nurses cannot manage" says Boy. Then they approach other organisations such as Right-to-Life to assist the practitioners, or the patients are referred to the hospital for further treatment. Defaulting paediatric patients is also a challenge because the children are dependent on the parent or other care taker to make sure that they get to the clinic at the right time.

Stigma and discrimination

Stigma and discrimination has changed drastically over time. Nurses who work with HIV patients are not discriminated against any longer and most nurses are now trained in HIV care. This has created more interest in the care of people living with HIV and the

availability of ARVs has changed the outcome of the disease significantly. This has made nurses more positive about HIV treatment and care.

While many patients attend their scheduled clinic visits, there are others who do not attend. "One wonders if they are getting their treatment" says Boy. The treatment taken by paediatric patients is centred around the family and it is sometimes seen that, because of stigma, the child is not taken to the clinic by the parent or carer because they do not want the child to be seen at the HIV clinic or getting HIV treatment. Even if they attend the clinic, it is not clear whether the child is getting the treatment at home. Sometimes someone else brings the child to the clinic to get his/her treatment.


What do you most enjoy in your work?

When asked what he enjoyed most in the work he does, Boy Mahlangu said "attending to paediatric patients, their treatment and identifying a crucial condition. I can call a second person to confirm the diagnosis and start the patient on treatment. A few weeks later I see a patient that is much better – that is what makes me happy!"

Continuous training of professionals

Boy Mahlangu is involved in providing in-service education on paediatric HIV care to other nurses. It is essential to remain updated because health interventions and particularly ARVs are changing rapidly. While most nurses are interested in providing care, there are those who just want to give treatment and who do not want to delay with the problem at hand. "This is probably the lack of confidence amongst nurses to manage patients living with HIV, particularly children" he says.

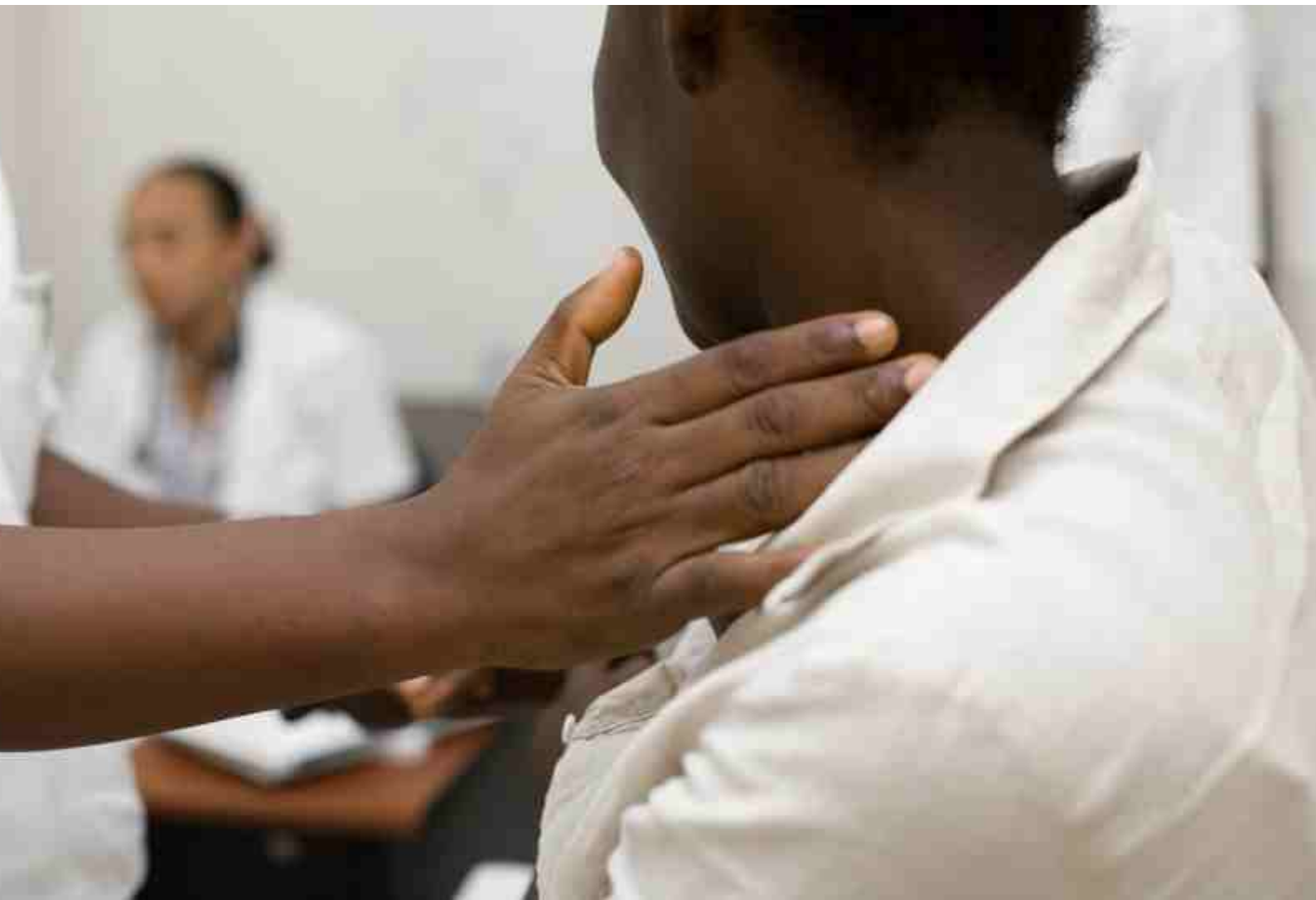
Message to other nurses

"All nurses have to stay abreast of new developments in HIV treatment and care because HIV touches all of our lives – it should be treated like any other chronic condition that can present with acute phases from time-to-time" says Boy. 



Improving Quality Primary Healthcare through Clinical Mentorship

By Courtney Istre, on behalf of the National Mentorship Task Team



Training without mentoring is no training - nurses who have accessed training without follow-up clinical mentoring and competency assessment should not be counted as NIM-ART trained healthcare workers. Nurses should also not be pressurised by their district teams to start initiating before feeling competent or confident - they should be provided with clinical mentoring before starting to initiate ART. This article describes the role of nurse-mentors and why it is necessary to promote quality primary healthcare.

In December 2009, the South African government set ambitious goals of testing 15 million people for HIV and expanding ART initiation to 2,000 primary healthcare facilities that previously could not offer this service. This required a drastic increase in the number of nurses trained in Nurse Initiated and Managed ART (NIM-ART); a policy designed to expand HIV treatment and care through task-shifting from the sparse quantity of physicians to the more robust cadre of nurses. NIM-ART training began in earnest in March of 2010; however, training alone proved inadequate to create competent and confident nurses in initiating ART. The clinical mentorship component became critically important.

Clinical Mentorship for Clinicians in South Africa

Clinical mentorship is a system of practical training and consultation that fosters ongoing professional development of mentees to deliver sustainable high-quality clinical care. Since this piece of the puzzle had not previously been an integral part of the training of health care workers in the public sector, it was essential to develop guiding documentation around this concept. In January 2011, the National Department of Health (NDOH), with contributions from various implementing partners and based on national policy and guideline documents, developed the *Clinical Mentorship Manual for Integrated Services*. This publication lays out the rationale and plan for establishing clinical mentorship programmes in public health facilities, and provides practical tools to assist in the process².

It is essential to have a competent healthcare workforce with the knowledge, skills and attitude needed to provide high quality primary care. Additionally, effective training, clinical mentorship, and ongoing supportive supervision ensure consistent application of national treatment guidelines and the provision of high quality care. By issuing this policy document, the NDOH acknowledges that classroom training is not sufficient to improve clinical practice and ensure competence in clinical practice. Partners, including local and international non-governmental

organisations (NGOs), have been advised that all NIM-ART training must be case-based and followed by clinical mentorship.

What is the Mentorship Manual?

The purpose of the *Clinical Mentorship Manual for Integrated Services* is to provide guidance to provinces, district and sub-district management teams (DMTs) in developing and/or integrating clinical mentorship programmes within the District Health System (DHS). Until this year, provincial and district departments of health were to design and implement their own respective mentorship programmes without national guidance or tools.

The manual covers such topics as "Clinical Mentorship Versus Supportive Supervision," "Goals and Objectives of Clinical Mentorship," "Development and Implementation of a Clinical Mentorship Programme at (Sub) District Level," "Who Should be a Clinical Mentor?" and "Clinical Mentorship Models," among others. But perhaps the most useful part of the document is the practical tools section in the Appendix.

Due to the burden of the HIV and AIDS epidemic in South Africa and the significant need for NIM-ART-trained nurses, three of the Appendix tools are specific to HIV and AIDS, TB and STIs, including the Clinical Competency Assessments by the Mentee and Mentor. Competencies related to other diseases

or programs will be developed at a later date, using the same methodology.

The Manual in Practice - Evaluation Tools

For practicing clinicians in the healthcare facility setting, the Manual contains a practical Tools section in the Appendix. Seven tools form the framework for clinical mentoring and help to assess required competencies of a nurse who will initiate patients on ART. These tools include:

- **I) Clinical Mentoring Agreement Form**, which sets the rules of engagement, expectations from both sides and agreement on the way forward;

- **IIA) Clinical Competency Assessment Form: Mentee Self-Assessment**, for the mentee to personally assess his/her own competence AND confidence in each clinical decision making skill specifically related to comprehensive management of HIV;

- **IIB) Clinical Competency Assessment Form: Clinical Mentor Evaluation of the Mentee**, for assessing and monitoring the development of the mentee based on the clinical mentor's observation;

- **III) Mentee Logbook for Case Management**, to register the type and number of cases a nurse manages



during the clinical mentorship process;

- **IV) Clinical Mentor Performance Standards**, to monitor and assess the performance of the mentor with regards to the set objectives, targets, methodology and approach;
- **V) Monthly Reporting Tool**, to communicate clinical mentoring activities to (sub) district management; and
- **VI) Checklist for Clinical Mentor's Responsibility**, to highlight the role and responsibilities of the clinical mentor.

Reaching Competency in NIM-ART

Clinical mentoring should be seen as part of the continued professional development required to create competent care providers. Driven by the learning needs of mentees, it occurs in face-to-face consultation, as well as through ongoing phone and email consultations. After initial didactic coursework, which imparts knowledge on a particular subject, the clinician responsible for providing quality care and treatment is provided mentoring at facility level to implement clinical standards (guidelines), addressing knowledge, attitudes, and behaviour and thereby competency.

One of the key components of the

Manual is the development and publication of the 54 Clinical Competencies/Tasks. These are of utmost importance to clinicians nationwide as they form the basis for determining if a provider, irrespective of cadre, is clinically competent to manage and initiate patients on ART. In the Mentorship Manual, these competencies are divided into four sections: All Care, Comprehensive Care of Adults and Children, Care Specific to Women, and Care Specific to Children. The mentee first assesses him/herself, using a scale of 1 - 4 for each task (1 being not confident through 4 being able to teach others). The clinical mentor then also ranks the mentees' competency on a separate form. This process is performed at the first mentor-mentee encounter and regularly (weekly/monthly) thereafter. A nurse clinician is deemed 'competent' in a competency or set of competencies if a score of 3 or 4 are measured by both the mentor and mentee.

The Paediatric Component

In South Africa there is concern related to district health capacity to treat HIV positive children, particularly due to the lack of adequate human resources comfortable with initiating and managing children on ART. Universal access to comprehensive HIV services will only be possible for children if Professional Nurses are empowered to initiate and manage ART. Integrated Management of Childhood Illnesses

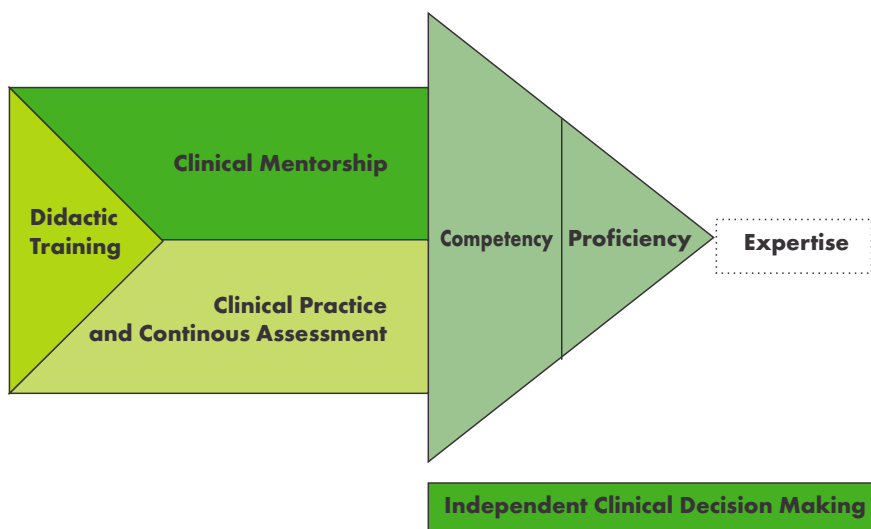


Figure 1: Clinical Proficiency Pathway

(IMCI) paediatric ART training is therefore a key component of NIM-ART competency development. The mentorship that follows the training specifically addresses competencies required for a clinician to effectively diagnose and treat children, as well as identify problems that need referral for more specialized care. The mentor assists and observes the mentee to master the competency and incorporate it into his/her practice. If there is

insufficient opportunity for the mentee to learn the specified skills at his/her own health facility, s/he should be provided the opportunity to see patients at another facility. This is particularly relevant in settings where few paediatric patients are encountered; it may be more time- and cost-effective for the nurse seeking to attain competency in paediatric treatment to practice in a paediatric clinic for several days.

Clinical Care Competencies in HIV and TB Across the Lifespan

Task/Competency		1 - 4	
Care Specific to Children	44	Correctly document in "Road to Health" card at every visit	
	45	Monitor growth, accurately plot weight, height, and head circumference on a growth chart on every visit	
	46	Demonstrate knowledge of immunisation schedule in HIV positive children	
	47	Determine HIV status of HIV-exposed children using DNA-PCR (dry blood spot)	
	48	Describe how, when, and why cotrimoxazole prophylaxis is given to HIV-exposed children	
	49	Determine WHO clinical stage of children, including calculation of percent weight loss and weight gain	
	50	Recognize and interpret developmental abnormalities in children	
	51	Diagnose and manage (treatment/referral) common & severe respiratory diseases in addition to those listed above: lymphocytic interstitial pneumonitis	
	52	Assist caregivers to disclose HIV status to children	
	53	Prescribe the correct ARVs for the first line regimens in infants and children according to national guidelines	
	54	Prescribe the correct drugs for TB/HIV co-treatment in infants and children according to national guidelines	

Figure 2: A snapshot of the competencies listed in the Clinical Competence Assessment tool

Training of Mentor's Curriculum Debut

In an effort to determine a national curriculum for the training of mentors (ToM), the Mentorship Task Team reconvened to review known existing ToM curricula used by Regional Training Centres (RTCs) and training partner organisations. This process is now complete and the national 3-day Training of Mentor's Curriculum is available from the National Human Resources and Strategic Programmes Department and can be accessed by emailing Thabile Msila (msilaT@health.gov.za). This includes training material such as the ToM Participant Handbook and ToM Trainer's Guide, now available for dissemination.

Conclusion

The importance of clinical mentorship is undisputed. The *Clinical Mentorship Manual for Integrated Services* is a vital tool in yielding competent nurses in their specific field, namely around HIV and AIDS, TB and STIs. Not only does it serve as a guide for (sub) district teams on how to develop and implement a mentorship plan, but it provides practical resources for mentors to utilize in the mentorship process. Through clinical mentorship, health care workers will continue to provide quality care to help realize the government's vision of "A Long and Healthy Life for All South Africans."

Reference List

1 <http://www.who.int/hiv/pub/meetingreports/clinicalmentoring/en/>
<http://www.who.int/hiv/pub/meetingreports/clinicalmentoring/en/>

2 Clinical Mentorship Manual for Integrated Services. January 2011. National Department of Health, Republic of South Africa.

* "When I first opened the manual and I noticed the list of 54 tasks/competencies in Tool IIB, I was a bit skeptical. 'This is not mentoring,' I thought, 'this is ticking boxes.' However, the more I looked at the whole manual, the more I realised how cleverly it has been put together to guide the mentor through the whole process of mentoring. I became even more convinced as I started using the manual to train nurse mentors. The nurses were delighted. At last they had a structure to mentoring that sets out both the process and the tasks. The manual guides the process in a clear, straightforward way that helps to achieve a confident and competent nurse who is able to initiate ART on his or her own. I would like to congratulate all those who have put so much work into writing this manual."

- David Cameron, MBChB M Prax Med MPhil

Multidisciplinary approach

to integrating treatment and care into ante-natal care in Kenya

By Teresia Mutuku, BSc Nursing, Technical Officer, Jhpiego-Kenya

Dr. Allan Gohole, HIV Advisor, Jhpiego-Kenya

Khadija Nalinya, Kenya Registered Community Health Nurse (KRCHN), Kenya Ministry of Health



This article reflects on the difference nurses made to the lives of HIV infected mothers and their babies – this is the story of the nurses at the Provincial General Hospital in Kakamega in Kenya

Nurses at the Provincial General Hospital in Kakamega in Kenya are making a difference in the lives of HIV-infected mothers and their babies exposed to HIV. Pregnant women who are HIV positive arrive at the Maternal and Child Health Clinic for antenatal care and, at the same time receive the care and treatment they need to protect their unborn children from HIV.

"We keep them in the MCH," says Khadija Nalinya, the community health nurse in charge of the Maternal Child Health (MCH) clinic at Kakamega.

Identifying the challenge

This focus on integrated care came after nurse leaders like Nalinya saw one too many HIV-positive women return to the hospital feverish and sick after giving birth. She had seen one too many babies die because their mothers hadn't received the treatment and care needed to protect their unborn child from the virus that causes AIDS. Women weren't returning to HIV comprehensive care clinics (CCC) for essential follow-up care, even after nurses had personally escorted them there for the initial visit.

"We discovered our work was not bearing fruit and we had to change," recalls Nalinya. "The nurses were so committed to escorting these mothers to the comprehensive care clinics individually, without wasting time, and making sure they are seen immediately. I would walk back singing because I have helped one more - until one day I met a mother in bad shape after delivery. I followed (her) up to know what had happened since I took her to the comprehensive care clinic. It hit me hard to discover that she never went back after the day I escorted her. She had given birth and the baby too was very sick and passed away shortly when after the mother was in the ward. Then, as a department, we wondered how many more had dropped out from the comprehensive care clinics".

The solution

"Our salvation came when we got information that Jhpiego's ACCESS Uzima program wanted to train the MCH and maternity nurses on HIV care using the IMAI (Integrated Management for Adult and Adolescent Illnesses) curriculum."



Figure 1 Antiretroviral drugs in one of the rooms in Maternal and Child Health clinic in Kakamega hospital.

In 2008, MCH staff from Kakamega received training in ART in preparation for integrating these services into routine maternal and child health care. They also performed a benchmarking visit to a functional MCH model at the national teaching and referral hospital where integration was taking place. Routine follow-up and supervision were provided by the USAID-funded APHIA II Western project team located in Kakamega where Jhpiego was the partner responsible for MCH interventions.

Hospital gynaecologists routinely mentored MCH nurses to administer ARVs for prophylaxis and treatment. The integration process began in July 2009 and the hospital received a visit in November of the same year by a team from the National AIDS and STI (Sexually Transmitted Infections) Control Program (NAS COP), the Division of Reproductive Health (DRH) and Jhpiego's Nairobi office who encouraged the nurses to continue.

In January 2010, the hospital started enrolling children into care in MCH. With support from management, drugs for both treatment and prophylaxis were made available in MCH services.

Rolling out the integration model

In collaboration with DRH and NAS COP, ACCESS Uzima started integrating ART in antenatal care ("MCH Model") at four other high volume hospitals. The model includes opt-out HIV counselling and testing for pregnant women, partner HIV testing, WHO clinical staging and CD4 testing. HIV positive mothers, their partners and exposed infants receive HIV care and treatment services at MCH until the baby is 18 months old.

The impact of the MCH Model

In Kakamega Provincial General Hospital during the six months before initiation of the MCH model, 47% of the 113 referred ANC HIV+ mothers registered for HIV services and only 15% returned after registration. The progress made since integration of HIV services into maternal and child health care is commendable.

Midwife Khadija Nalinya takes weight of a pregnant mother Since Kakamega Provincial General Hospital launched the MCH Model in July 2009 (structured follow-up for infants commenced in January 2010) and up to December 2010, the following has been achieved:



Midwife Khadija Nalinya takes weight of a pregnant mother

- 6,720 pregnant women were tested for HIV
- 315 were found to be HIV positive, and **every one of them** had CD4 counts, clinical staging and Prevention-with-Positives counselling done
- 79 women (25%) needed treatment for their own health ($CD4 \leq 350$ or WHO clinical stage 3 or 4), and **every one of them** initiated HAART during pregnancy
- 82% of these women are still on HAART (one client died before delivery)
- 63 (80%) mothers on HAART delivered and **all infants were tested** and found to be negative by PCR at 6 weeks
- 15/15 (100%) of babies tested at 1 year remain HIV negative
- 6 mothers with HIV negative children at 18 months transitioned to the adult HIV care and treatment services at KPGH
- Only 5 mothers have been lost to follow-up

The MCH model has improved access to ART and related HIV services for mothers and infants and appears to have reduced mother-to-

child-transmission in Kakamega. This model can be replicated in Kenyan public hospitals if staff are adequately trained and supported. Scaling up the model across the region would ensure pregnant women have access to patient-centred, integrated, comprehensive HIV care and treatment services for their own health, not only to prevent transmission of HIV to their babies.



This is our joy: HIV negative child

Acknowledgement:

Jhpiego-Kenya would like to acknowledge the commitment and dedication of Kakamega Hospital management and clinical staff, as well as funding support by USAID to ensure women and their children have access to life-saving interventions.

R

INTEGRATION OF HIV CARE

into ante-natal care has improved access to HIV treatment and care in Kenya



to advertise in

HIV Nursing matters

By advertising in HIV Nursing, you reach many partners in the health industry.

Rates for 2011 are as follows:

Size	Full colour
Full page/Volblad	R 7 200-00
Half page/Halfblad	R 3 850-00
Third page/Derde blad	R 2 500-00
Quarter page/Kwartblad	R 2 030-00

Rates are subject to change

Inserts & promotional articles

The same rate as for advertisements applies to articles and inserts
Small advertisements: Available on request
These prices exclude VAT and advertising agency commission.

Digital advertising material formats.

The following are formats by which the magazine can accept digital advertisements:

- Document to be set up to advertising specifications (i.e. Ad specs)
- We don't support zip disks
- Emailed advertising material should not be bigger than 5MB (PDF, Jpeg or tiff)
- All advertising material to be in CMYK colour mode and the resolution 300 dpi
- If pictures are sent, save as high resolution (300DPI)
- Logos must be 300 dpi with a CMYK colour Breakdown
- All advertising material must have a 5mm bleed
- Press optimised PDF's on CD with a colour proof is also acceptable.
- PDFs supplied should include all fonts and in CMYK mode.
- PLEASE SUPPLY MATERIAL IN COMPLETED PDF FORMAT
- PLEASE ENSURE THE AD INCLUDES CROPMARKS!!!

SA HIV Clinicians Society

Suite 233, PostNet, Killarney
Private Bag X2600, Houghton, 2041

www.sahivsoc.org

Tel: +27 (0) 11 341 0162,
FAX: +27 (0) 11 342 0161

Article/letter submissions: nelouise@sahivsoc.org



CLINICAL TIPS FOR NURSES

FROM THE NATIONAL HIV & TB HCW HOTLINE



Prescribing antiretrovirals in patients with renal impairment

Tenofovir is well known to cause renal toxicity. Before initiating your patient on the first-line regimen of tenofovir (TDF), lamivudine (3TC) and efavirenz (EFV) or nevirapine (NVP) it is important to consider your patient's renal function. It is essential to calculate the creatinine clearance in all patients who start tenofovir with weight < 50kg or age > 50 years or a serum creatinine of > 100 µmol/L. Patients who do not meet any of the aforementioned criteria are likely to have normal renal function.

Presented here are two of many methods for determining renal function. The glomerular filtration rate can be estimated – laboratories report this as the eGFR, or the creatinine clearance can be estimated using a Modified formula of Cockcroft and Gault (recommended by the South African Renal Society):

$$\frac{[140 - \text{age}(\text{years})] \times \text{weight}(\text{kg})}{\text{Serum creatinine}(\mu\text{mol/L})}$$

For females multiply the answer above by 0.85

Note that these two methods will give different results in the same patient, but the estimates are accurate enough for clinical decision-making. Any patient with an eGFR or creatinine clearance (CrCl) of less than 50 mL/min should NOT be given tenofovir. In addition, remember that a normal eGFR/CrCl is actually above 80 mL/min, so patients with a value between 50 and 80 mL/min already have compromised renal function. Patients with an eGFR/CrCl below 50 mL/min should be referred to a doctor to assess the cause of the renal failure and for initiation of ART. The national guidelines recommend

Adjustment of dosages of antiretrovirals in patients with renal impairment

Drug	Standard Dose	Dosing in renal impairment		
Abacavir	300 mg twice daily	Dosage adjustment not needed		
Didanosine (enteric coated)	250 mg to 400 mg per day, depending on weight	CrCl/eGFR (mL/min)	Wt ≥ 60 kg	Wt < 60kg
		≥ 60	400 mg daily	250 mg daily
		30-59	200 mg daily	125 mg daily
		10-29	125 mg daily	125 mg daily
		< 10	125 mg daily	Formulation not suitable
Efavirenz	600 mg daily (or 400 mg if < 40 kg) at night	Dosage adjustment not needed		
Lamivudine	150 mg twice daily or 300 mg once daily	CrCl/eGFR (mL/min)		
		≥ 50	150 mg twice daily or 300 mg once daily	
		30-49	150 mg daily	
		15-29	150 mg first dose, then 100 mg daily	
		5-14	150 mg first dose, then 100 mg daily	
		< 5	50 mg first dose, then 25 mg daily	
Lopinavir/ritonavir (Aluvia®/Kaletra®)	400mg/100mg twice daily	Dosage adjustment not needed.		
Nevirapine	200 mg daily for 2 weeks then 200 mg twice daily	Dosage adjustment not needed.		
Stavudine	30 mg twice daily	CrCl/eGFR (mL/min)		
		> 50	30 mg twice daily	
		26-50	15 mg twice daily	
		< 25	15 mg once daily	
Tenofovir	300 mg once daily	CrCl/eGFR (mL/min)		
		< 50	DO NOT USE	
Zidovudine	300mg twice daily	CrCl/eGFR (mL/min)		
		≥ 15	Dosage adjustment not needed	
		< 15	300mg daily	
Please note that for patients on haemodialysis these recommendations may be different The table includes all ARV classes CrCl = Creatine Clearance				

assessing renal function at baseline before initiating TDF and then again at three months.

Tenofovir is not the only antiretroviral which is influenced by the patient's renal function. All nucleoside reverse transcriptase inhibitors (NRTIs) or their metabolites are excreted by the kidney and many of them need their doses to be adjusted according to the degree of renal impairment. Use the table above to assist you with the correct dosing for your patient.

Also, remember that HIV can cause

renal dysfunction and as your patient responds to ARVs their renal function may improve and the doses should be adjusted upwards, otherwise the patient's drug levels may become sub-therapeutic.

References:

McNicholl IR, Rodriguez RA. Dosing of Antiretroviral Drugs in Adults with Renal Insufficiency and Hemodialysis, <http://www.aidsetc.org/aidsetc?page=et-03-00-02> (Accessed, April 2011)
McEvoy GK, Snow EK et al. AHFS Drug Information 2011. Bethesda, Maryland, USA
National Department of Health. Clinical Guidelines for the Management of HIV & AIDS in Adults and Adolescents. 2010. South Africa.

HIV CAN
cause renal dysfunction which may improve as the patient responds to treatment and doses should be adjusted upwards



Toll-Free National HIV & TB Health Care Worker Hotline

Are you a doctor, nurse or pharmacist?

Do you need clinical assistance with the treatment of your HIV or TB patients?

Contact the TOLL-FREE National HIV & TB Health Care Worker Hotline



**0800 212 506 /
021 406 6782**

Alternatively send an SMS or
"Please Call Me" to 071 840 1572
www.hivhotline.uct.ac.za



The Medicines Information Centre (MIC) situated within the Division of Clinical Pharmacology, Department of Medicine at the University of Cape Town is the largest and only clinically-based medicine information centre in South Africa.

In collaboration with the Foundation for Professional Development and USAID/PEPFAR, the MIC provides a toll-free national HIV & TB hotline to all health care workers in South Africa for patient treatment related enquiries.

What questions can you ask?

The toll-free national HIV & TB health care worker hotline provides information on queries relating to:

- HIV testing
- Post exposure prophylaxis: health care workers and sexual assault victims
- Management of HIV in pregnancy, and prevention of mother-to-child transmission
- Antiretroviral Therapy
 - When to initiate
 - Treatment selection
 - Recommendations for laboratory and clinical monitoring
 - How to interpret and respond to laboratory results
 - Management of adverse events
- Drug interactions
- Treatment and prophylaxis of opportunistic infections

- Drug availability
- Adherence support
- Management of tuberculosis and its problems

When is this free service available?

The hotline operates from Mondays to Fridays 8.30am – 4.30pm.

Who answers the questions?

The centre is staffed by specially-trained drug information pharmacists who share 50 years of drug information experience between them. They have direct access to:

- The latest information databases and reference sources
- The clinical expertise of consultants at the University of Cape Town's Faculty of Health Sciences, Groote Schuur Hospital and the Red Cross War Memorial Children's Hospital



**MEDICINES
INFORMATION
CENTRE**



NDOH/SANAC Nerve Centre Hotlines

• Any HCT concerns from facility and district managers should be reported to the NDOH/SANAC

Nerve Centre Hotline and, specific emails for each province:

- **Western Cape:** 012-395 9081
sanacwesterncape@gmail.com
- **Northern Cape:** 012-395 9090
sanacnortherncape@gmail.com
- **Eastern Cape:** 012-395 9079
sanaceasterncape@gmail.com
- **KZN:** 012-395 9089
sanackzn@gmail.com
- **Free State:** 012-395 9079
sanacfreestate@gmail.com
- **Mpumalanga:** 012-395 9087
sanacmpumalanga@gmail.com
- **Gauteng:** 012-395 9078
sanacgauteng@gmail.com
- **Limpopo:** 012-395 9090
sanaclimpopo@gmail.com
- **North West:** 012-395 9088



AIDS Helpline 0800 012 322

The National AIDS Helpline (0800-012-322) provides a confidential, anonymous 24-hour toll-free telephone counselling, information and referral service for those infected and affected by HIV and AIDS.

The helpline was initiated in 1991 and is a partnership of the Department of Health and **LifeLine Southern Africa**. The Helpline, manned by trained lay-counsellors, receives an average of 3,000 calls per day, and is seen as a leading telephone counselling service within the SADC region.

Services Offered by the AIDS Helpline:

- Information: The Line creates a free

and easy access point for information on HIV and AIDS to any member of the public, in all of the 11 official languages, at any time of the day or night.

- **Telephone Counselling:** Trained lay-counsellors offer more than mere facts to the caller. They are able to provide counselling to those battling to cope with all the emotional consequences of the pandemic.
- **Referral Services:** Both the South African Government and its NGO sector have created a large network of service points to provide a large range of services (including Voluntary Counselling and Testing, medical and social services) to the public. The AIDS Helpline will assist the caller to contact and use these facilities. The National AIDS Helpline works closely with the Southern African HIV Clinician's Society to update and maintain the **Karabo Referral Database**. www.sahivsoc.org
- **Treatment Line:** A specialised service of the AIDS Helpline, the Treatment Line, is manned by Professional Nurses. They provide quality, accurate and anonymous telephone information and/or education on antiretroviral, TB and STI treatment. They also provide relevant specialised medical referrals to individuals affected and infected by HIV and AIDS in South Africa.





**NATIONAL HEALTH
LABORATORY SERVICE**

RESULTS HOTLINE

0860

RESULT 737858

This line is dedicated to providing results nationally for HIV Viral Load, HIV DNA PCR and CD4 to Doctors and Medical Practitioners, improving efficiency in implementing ARV Treatment to HIV infected people. This service is currently available to members of Health Professionals Council of the South Africa and the South African Nursing Council. The hotline is available during office hours from 8am to 5pm Monday to Friday.

Register to use the RESULT HOTLINE

Follow this simple Step-by-step registration process

Dial the **HOTLINE** number **0860 RESULT (737858)**

Follow the voice prompts and select option 1 to register to use the hotline

A hotline registration form will be sent to you by fax or e-mail.

Complete the form and return it by fax or e-mail to the hotline to complete your registration process.

Once you are registered, you will be contacted with your unique number. This number is a security measure to ensure that the results are provided to an authorized user.

To use the hotline dial **0860 RESULT (737858)**

Select option 2 to access laboratory results.

- You will be asked for your HPCSA or SANC number by the operator.
- You will be asked for your Unique Number.
- Please quote the CCMT ARV request form tracking number (bar coded) and confirm that the result requested is for the correct patient.

Should the results not be available when you call, you will be provided with a query reference number which must be used when you follow up at a later date to obtain the result.

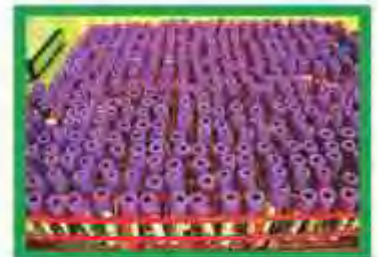
Once you have a Reference number

Select option 3 to follow up on a reference number

Should the requested results not be available, a query reference number will be provided to you.

A hotline operator will call you within 48 hours of receiving the laboratory results.

Registering for this service from the NHLS, will assist in improving efficiency, providing improved patient care and streamlining clinic processes. Call now and register to access results for HIV Viral Load, HIV DNA PCR and CD4.





Competition

A Day in the Life of a Rural Nurse

Nurses country-wide are working under enormous strain; many of their challenges were well captured in the Nursing Compact of April 2011. The growing burden of disease, the need for task-shifting, staffing shortages, poorly maintained facilities and drug stock-outs are but some of the challenges nurses are faced with on a daily basis. These problems are often amplified in the rural areas where resources are less and poverty levels are higher. Where distances are large and infrastructure poor or absent all together. With quality of care and nursing attitudes under attack, we call for rural nurses to share with us a day of their life "in rural practice". Tell us what you love about your work; and what are

your daily challenges in providing quality care? In doing so, let us know how you would strengthen the local health system and how do you see the support roles of other health care workers?

Submit your max 1000 piece TYPED word document to Laurie Schowalter at laurie@sahivsoc.org by 1 December, 2011 and stand a chance of having your piece published in *HIV Nursing Matters* and winning a new cellphone.

This competition is offered by the SA HIV Clinicians Society and the Rural Health Advocacy Project.

The Rural Health Advocacy Project (RHAP) is an advocacy organisation in the field of rural

health care. RHAP's work revolves around the right of rural and remote communities to have equitable access to comprehensive, quality health care. The Rural Health Advocacy Project is a partnership initiative between the Rural Doctors Association of Southern Africa (RuDASA), the Wits Centre for Rural Health (WCRH) and Section27, incorporating the AIDS Law Project. www.rhap.org.za

By participating you agree to have your picture taken and story published. The judges' decision is final and no correspondence will be entered into. Please note that only typed stories will be considered.

Rural Health
Advocacy Project

Hospice Palliative Care Association of SA



Short Course in Palliative Nursing for Professional and Enrolled Nurses run in conjunction with the Hospice Palliative Care Association of SA and the Foundation of Professional Development.

INTRODUCTION

The WHO defines palliative care as “an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psycho-social and spiritual.”

Palliative care is an integral part of every nurse's role. This course equips the nurse with the particular skills and knowledge required to care for patients with non-curable and terminal illness and to support the patient's family members. This short course is run as a collaborative venture between HPCA and FPD.

WHO SHOULD ENROL?

All professional and enrolled nurses registered with the SANC who care for patients with life-threatening illness.

ASSESSMENT / CERTIFICATION

Formative and summative assessment methods are used to evaluate learning at both theoretical and practical levels. To qualify for the certificate of completion for this short course, participants should fully attend the workshops, successfully complete the assessment process and complete the clinical work.

COURSE DESIGN

The course consists of 3 parts:

1. Day release learning based on methods suitable for adult learners.
2. Assessment component (examination, communication skills and portfolio).
3. 128 hours clinical work – done in a HPCA approved Hospice.

COURSE STRUCTURE

1. Describe the development of palliative care and its role within the health care system and apply legal, ethical and professional principles in the care of patients and families, with particular reference to death and dying.
2. Describe the management principles of pain and symptom control in advanced illness with particular reference to malignant disease, HIV and AIDS, progressive neurological disorders and end stage organ disease.
3. Be competent in the interpersonal communication skills required to establish rapport and facilitate the grieving process with patients, families and colleagues.
4. Demonstrate the ability to understand the developmental stages as applied to social, cultural and spiritual dimensions in the provision of palliative care based on respect for the uniqueness of the individual.

Starting date:

February - 2012
 Day Release: 9 February 2012
 Distance Learning: 6 February 2012

REGISTRATION

Educational Grant

This course is partially sponsored through an educational grant from HPCA

All interested nurses can apply for this grant from:

LeshokoKomane

Tel: 012 664 8538
 Fax to email: 086 513 9814
 Email: lesoko@hpca.co.za

COURSE FEE

R 6 740

A member of the SAMA group



Registered with the Department of Education as a private Institution of Higher Education under the higher education act, 1997 (Registration number: 2002/HE07/013)

Foundation for Professional Development (Pty) Ltd Registration number 2000/002641/07

living AND loving

Since 1996
**Sensitive
Midwifery**

SYMPOSIUM™
SOUTHERN AFRICA

2011

THE CONFERENCE FOR

Childbirth Educators & Midwifery Lecturers
Independent & Labour Ward Midwives
NICU, Postnatal & Baby Clinic Nurses
Student Midwives
Other Obstetric & Babycare Professionals

brought to you by

**PHILIPS
AVENT**

GAUTENG • EASTERN CAPE • MPUMALANGA • WESTERN CAPE • NORTH WEST

2011 PROGRAMMES

Midrand, Gauteng 25 February 2011	
Session Time	What's on?
07h00 – 08h00	Registration
08h00 – 08h15	Opening
08h15 – 10h45	Putting Third Stage First Plus other obstetric mythbusters
	Midwives, Moms & Multiples How to help in pregnancy & beyond
	Infant Digestive Discomfort Understanding colic and nutritional solutions
10h45 – 11h15	Tea
11h15 – 13h00	Neuroscience to Improve Neonatal Care With Nils & Jill Bergman
	The Alpha & Omega of Essential Fatty Acids Message from DENOSA
	Monitoring Mothers & Unborn Babies Plus Obstetric concerns Q&A with Prof Justus Holmney
13h00 – 14h00	Lunch
14h00 – 16h45	The Permanent Impact of Gentle Babycare
	Breastfeeding, Sexuality & Contraception
	Conclusion & prizes galore!

Port Elizabeth, Eastern Cape 20 May 2011 Rustenburg, North West Province 28 October 2011	
Session Time	What's on?
07h00 – 08h00	Registration
08h00 – 08h15	Opening
08h15 – 10h30	Handling HIV in NICU A sensitive issue
	Intuitive Perinatal Errors Evidence supports parent power
	A Mom's Story
10h30 – 11h00	Tea
11h00 – 13h30	Contagious Disease Management in Pregnancy
	Breastfeeding with Joy, Confidence & Success Help launch mothers onto the journey of lactation
	Putting Pressure on Postpartum Haemorrhage
13h30 – 14h30	Lunch
14h30 – 16h45	Gastro-Intestinal Health Central to a baby's well-being
	Understanding Pain in Labour Plus Lesser practiced but proven relief techniques
	Supplementation Safety in Pregnancy
16h45 – 17h00	Conclusion & prizes galore!

Nelspruit, Mpumalanga 29 July 2011 Somerset West, Western Cape 9 September 2011	
Session Time	What's on?
07h00 – 08h00	Registration
08h00 – 08h15	Opening
08h15 – 10h30	The Essentials of Aromatherapy Message from DENOSA
	Respiratory Distress in Neonates Plus a mini-resuscitation course
	Tea
10h30 – 11h00	The Significance of the Partograph Expertise update
	Percentiles, Growth Curves & Baby Development Use, don't abuse!
	Breastfeeding When Everyone Says 'Impossible' Adoption, multiples, breast surgery, HIV infection
11h00 – 13h30	Lunch
13h30 – 14h15	Lunch
14h15 – 16h45	An Inspiring Midwifery Story
	Making Normal Birth & Postnatal Care Natural Improve patient & professional experience
	Mental Health in Mothers Essential for a healthier family & nation
16h45 – 17h00	Understanding how Parents' Brains Work With Nils & Jill Bergman
	Conclusion & prizes galore!

(T) +27(0)12 348 4992 • e-mail: info@sisterlilian.co.za (F) +27(0)12 348 8967



FPD

**FACULTY OF
HEALTH SCIENCES**

**BUILDING A BETTER
SOCIETY THROUGH
EDUCATION AND
DEVELOPMENT**

ENROL NOW FOR THESE CLINICAL COURSES

ACCREDITATION

Registered with the Department of Education as a private Institution of Higher Education under the higher education act, 1997 (Registration number: 2000/HE077111)

FPD was established in October 1997 by the South African Medical Association and has since then placed a high emphasis on developing the clinical skills and leadership ability of SA's Nurses. Below are a few courses that will be beneficial to Nurses.

SHORT COURSES

**COURSE IN
ICD-10 CODING**

This 1 day workshop will enable Health Care Professionals & administration staff to acquire knowledge, and update skills with regards to:

- Background to ICD-10 coding
- Benefits of clinical coding
- Basic structure and principles of ICD-10 coding
- Rules and conventions of ICD-10 coding
- Accuracy in coding
- Practical applications

CERTIFICATION: To qualify for a certificate of attendance, participants should fully attend the workshop.

COURSE FEE: R 1 950 This includes everything except travel costs (inclusive of all VAT and taxes where applicable)

DATE AND VENUE: 19 August 2011 Pretoria

**COURSE IN
DIAGNOSTIC ULTRASOUND**

This 2 day workshop will enable Health Care Professionals to acquire knowledge, update skills and enable them to:

- Choose ultrasound equipment
- Identify the organs in the abdominal cavities, normal abdominal and gynaecological ultrasound anatomy
- Recognise abdominal structures in multiple planes
- Correctly orientate the ultrasound image
- Recognise the sectional ultrasound anatomy in the transverse and longitudinal planes
- Utilise the basic abdominal protocol
- Describe the patient preparation and position
- Interpret ultrasound findings in common abdominal and gynaecological pathologies
- Use guidelines in obstetrical ultrasound
- Recognise normal ultrasound foetal anatomy
- Recognise common ultrasound foetal anomalies
- Recognise early ultrasound foetal failure
- Recognise ultrasound ectopic pregnancy
- Document ultrasound
- Demonstrate ultrasound imaging
- Understand the criteria for quality
- Understand the capabilities and limitations of ultrasound

CERTIFICATION: To qualify for a certificate of completion, participants should fully attend the workshop as well as successfully complete all forms of assessment.

COURSE FEE: R 4 500 inclusive of VAT and taxes where applicable

DATE AND VENUE: 15-16 October 2011 PEI&H November Pretoria

DISTANCE COURSES

**DISTANCE COURSE IN CLINICAL MANAGEMENT OF
HIV/AIDS FOR HEALTHCARE PROFESSIONALS**

This course will enable participants to acquire or update skills with regard to:

- The diagnosis of HIV/AIDS and STD's
- The management of HIV/AIDS and STD's
- All aspects of counseling (pre and post test, therapy compliance)
- Having empathy with people "Living with AIDS"
- Fulfill their role as health care professionals in community mobilization
- Understand vaccine development and clinical trials

CERTIFICATION: To qualify for the certificate of completion for this short course, participants should successfully complete the assessment process.

COURSE FEE: R 1 200 Inclusive of all VAT & taxes where applicable.

This includes all study material & assessment

**DISTANCE
DISPENSING COURSE**

At the end of the course you will be able to:

- Identify and apply ethical, legal and therapeutic considerations in all facets of dispensing.
- Evaluate prescription and access patient profile
- Dispense the prescription.
- Manage the procurement and storage of medicines
- Advise patients to ensure quality use of medicines and improve health status

CERTIFICATION: To qualify for a certificate of completion, participants should successfully complete the assessment process.

COURSE FEE: R 1 539 Inclusive of all VAT & taxes where applicable.

This includes all study material & assessment

REGISTRATION

EVELYN MAKAMA / MELANY MANOHARUM

Tel: 012 816 9100 / 9113

Fax: 012 807 7165

Email: melanym@foundation.co.za

evelynm@foundation.co.za

Website: www.foundation.co.za

PLEASE VISIT OUR WEBSITE FOR INFORMATION ON OTHER COURSES

Member of the SAMA group

