CLINICAL MODELS OF HIV CARE FOR ADOLESCENTS

INTERNATIONAL AIDS SOCIETY SATELLITE SESSION

AIDS 2016 – 18 July 2016

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BACKGROUND AND OBJECTIVES

Reducing new infections and AIDS-related deaths among adolescents is a key component of the global plan to end the AIDS epidemic by 2030. The satellite session prior to the start of the 21st International AIDS Conference (AIDS 2016) in Durban, South Africa, was aimed at providing a platform for researchers, health care professionals and programme implementers to discuss promising clinical care practices for adolescents, assess replicability in different contexts and identify options for adaptation, where required. The symposium was designed to both strengthen the evidence base through the presentation of new research on adolescent HIV services, and help address key gaps in adolescent HIV prevention and care by improving knowledge among practitioners of targeted approaches. The specific learning objectives were to understand:

a) Strengths and weaknesses of different models of clinical care and how this affects the prevention, care and treatment outcomes for adolescents
b) How HIV care services are experienced by adolescents living with HIV and what kind of support they need
c) How HIV services and health care professionals can support the optimization of clinical care delivery.

The session co-chairs were Rachel Vreeman from Indiana University, United States, and Carlo André Oliveras Rodriguez from the Adolescent HIV Treatment Coalition, Puerto Rico. Rachel Vreeman introduced the session, explaining that its focus was the context in which adolescent HIV care takes place. A short film from Kenya (Hiv-films.org) was shown, illustrating the challenges in the life of an HIV-positive adolescent boy, and the stigma and exclusion experienced at the community level.

Presentation 1: “Taking them forever and taking them on time”: The treatment and care needs of adolescents living with HIV

Janet Bhila, from the Global Network of Young People Living with HIV (Y+), Zimbabwe, spoke on the treatment and care needs of young people, presenting the findings of a consultation conducted in 2014, led by Y+ and supported by GNP+ and WHO. The study explored HIV-positive adolescents’ thoughts and feelings on taking ARVs.

The consultation comprised four workshops in four African countries, with a total of 84 participants. An anonymous online survey was conducted in five languages with 386 respondents from 30 countries. Of these, 117 respondents were eligible for inclusion because they: 1) were living with HIV; 2) were aged between 15 and 29 years; and 3) had experience taking ARVs as an adolescent. The workshops and survey focused on the following areas: 1) understanding adolescents’ everyday lives on ARVs; 2) challenges and benefits of ART; 3) missing/stopping ART; 4) information and support for adherence; and 5) services.

Findings related to adolescents’ narratives on the challenges and inconveniences of taking medication. One key challenge that was cited was the frequency and timing of taking medication around their daily activities and the restriction this places on their lives. Everyday activities, including sleep, travel, going out to have fun and being at school, were mentioned as barriers to taking ARVs on time. Adherence was cited as being particularly problematic for youth at boarding school; due to the lack of privacy, people would inevitably ask questions when taking medication. To avoid questions, adolescents often fail to adhere to their regimens. Another major issue cited was the experience of side-effects, particularly those with physiological impact, such as body shape changes, including developing breasts if male or developing a large upper body. Adolescents found these physical changes especially hard to cope with in a period of life when they have heightened self-consciousness about physical appearance.
The physical properties of ARVs, such as size, shape, number and taste of pills, were also cited as a major hindrance to adherence. Suggestions from respondents to improve adherence included smaller size, better taste and using differing colours for identification. Less frequent dosing was also suggested, for example, monthly or yearly doses.

“I hate it that ARVs are to be swallowed every day. I wish it was an injection ... once in a year.” (Female, aged 22, Uganda)

Adolescents expressed an awareness of the benefits of ARVs in enhancing health and well-being, enabling participation in everyday life.

“It reassures me to not get sick.” (Male, aged 20, Burundi)

A total of 81% of respondents acknowledged that ARVs keep them healthy, prevent new infections and give them strength to carry on with their work/study. Despite acknowledgement of the potential for ARVs to prolong life, adolescents also felt a lack of hope about their future.

“I accept my sero-status but my dreams are shattered.” (Female, aged 17, Zimbabwe)

Among survey participants, 35% indicated that they had stopped taking ARVs intentionally at least once. Likewise, one-third of workshop participants confirmed that they had intentionally stopped taking ARVs. Among the various reasons adolescents listed for stopping ARVs was that they did not want to be seen taking them. When asked about their feelings after missing ARVs, guilt and fear dominated the responses in both the workshops and survey.
Due to the burden of taking a life-long treatment, adolescents described feeling depressed, facing HIV-related stigma and/or judgmental attitudes of health providers. Interruptions in treatment adherence varied in length from one month to two years and were generally undertaken without consultation with health providers.

The findings demonstrated that HIV-positive youth need better information and more support. While friends, family members and health facilities are preferred for discussing ARVs and HIV, most information comes from health facilities and support groups, followed by the internet and family. The least common source of information was sexual partners.

Findings show that adolescents need practical strategies to improve adherence and to feel supported, such as face-to-face support through counselling, treatment buddies, sessions involving parents/guardians and role models. HIV-positive adolescents would also benefit from reminders and triggers to stay in the health system and keep taking their medication.

“Help us meet as groups and share our experiences [as opposed to] when someone stays at home thinking they are alone.” (Male, aged 18, Zimbabwe)

“If parents can “man-up” and tell their kids what they are living with, this will help adherence and ease the burden of the need for second line [ARVs].” (Female, aged 24, Kenya)

Some of the respondents described positive experiences of having accessed health care services, including feeling cared for while receiving services and receiving ARVs. Adolescents felt happy when they were given time to express their concerns and to talk.

“Yes [I am happy] because I’m given the time to express everything that would be bothering me and just have a talk in general.” (Female, aged 24, Zimbabwe)

HIV-positive adolescents face various barriers to timely and appropriate access to health care services. One barrier cited was missing school to attend clinics and get ARVs; everyone at school would know why you’re absent. Other barriers included distances to services, drug stock-outs, out-of-pocket expenses, lack of access to viral load or CD4 testing, and a lack of adolescent-focused sexual and reproductive health services.

“There is no privacy and we are mixed up with adults.” (Female, aged 18, Burundi)

Some adolescents who had managed to access health care recounted their negative experiences, including long waiting times and negative or judgmental attitudes of health providers. Adolescents complained about situations in which they would “just be given ARVs”, and not given the opportunity to ask questions or discuss problems.

“The service providers ill-treat us, they shout at us as if we applied for the virus ... they think we got it through being promiscuous. We are painted with one brush.” (Female, aged 22, Zimbabwe)
“Health services are not friendly and not every young person is empowered like me to stand for himself/herself and get quality services.” (Female, aged 17, Uganda)

Overall, available services are not orientated to adolescents. Another issue is that adolescents are not oriented in transitioning from being an adolescent to an adult and often feel lonely when moved as individuals to the adult sections.

Recommendations to improve services included:

- The provision of services and information from an early age, especially regarding SRH and disclosure
- Flexible appointment systems around school times
- Services that are free and closer to home in the community to improve access
- Dedicated adolescent services, at specific times, in separate areas, and safe and stigma-free environments
- Peer interventions (support groups and adolescents involved as providers)
- Comprehensive services that address their needs beyond HIV, such as psychosocial support, SRH and nutrition
- On-going effective support and environments that provide opportunities for open, honest discussion and information
- Support and counselling that ensures understanding of their status, improves knowledge and is empowering and solutions focused
- Skills development and support on disclosure and safer sex
- Dedicated, consistent, friendly, trained and competent providers who understand their needs and can communicate effectively.

In conclusion, it was stated that the transitional nature of adolescence and the daily realities of the lives of HIV-positive adolescents must be considered. Adolescents live with the knowledge that ARVs prolong their life, but they also live with stigma, fear and the daily reality of taking treatment. The lack of adolescent-friendly services and psychosocial support compound their struggles. Adolescents need a holistic response from the health system to adhere to treatment and remain in care, including adolescent-friendly services and strong networks of peer support. There is a need for further research, including operational research, on innovative strategies for treatment adherence, integrated service delivery and psychosocial interventions.

Presentation 2: Zvandiri CATS model: Findings from a community peer support treatment intervention in Zimbabwe

Nicola Willis, from Africaid Zvandiri Harare, Zimbabwe, presented on a project that started as a support group for adolescents living with HIV (ALHIV) in 2004. Run by volunteers, Zvandiri (“as I am” in Shona) provides community HIV prevention, treatment, care and support for people aged 6 to 24 years. This ensures that an integrated package of services is available for children, adolescents and young adults with HIV, available at point of need, and integrated within health facility services, providing differentiated care service. The Government of Zimbabwe has since adopted the model and scaled it up nationally.

Community Adolescent Treatment Supporters (CATS) are young HIV-positive people (aged 18-24 years) who work between health facilities and the homes of youth living with HIV (YLHIV) to increase uptake of testing, linkage and retention in care, adherence and services related to sexual and reproductive and mental health. CATS also track adolescents into care and provide differentiated care according to different needs. If youth are doing well, they get support and reminders. Those who are struggling, failing adherence or not attending, get placed into the enhanced/intensive group, and CATS then step up support. CATS are integrated with health facilities supervised by the Ministry of Health (MoH), and work closely with social workers, community health workers and clinic health workers. They also work to integrate support between clinics and homes.
A small operations research study was conducted in Gokwe South, a rural district of northern Zimbabwe. The study sought to measure the effectiveness of a community-based, adolescent-led treatment support and psychosocial intervention in improving: 1) retention in care; 2) adherence; and 3) psychosocial well-being. The study enrolled 50 adolescents on ART receiving standard of care versus 50 receiving standard of care plus CATS.

The study found that there was improved adherence from 44.2% at baseline to 71.8% at endline (p-value=0.0087) in those receiving CATS services. In addition, they were 3.9 times more likely to adhere to treatment than the control group (OR=3.934).

“It is now my desire to keep the virus suppressed because I really know now how these ARVs work. Even when you are well I have learnt the importance of taking ARVs from the CATS who visit me at home. My grandmother loves [these] CATS as they have really supported me and [I] am no longer having challenges to adhere to my ARVs.”

(Adolescent, Krima Clinic)

“I used to throw away my medicines, not adhering at all, but ever since I received support from the CATS I am now adhering to my medicines” (Adolescent, Sesame)

“Mabel always checks on me so I now understand the reason why I need to adhere so I thank her for the support. She is my pillar of strength.” (Adolescent, Krima)

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The intervention also improved linkage and retention among those receiving CATS services.

“CATS link adolescents to HTS, OI services, family planning and for clinical assistance. They feel more comfortable now accessing services and generally linkages to services has improved.” (District Medical Officer)

“The CATS programme has resulted in reduced loss to follow up since each CATS has a number of children he or she looks after and follows up on.” (Sister in Charge, Health Clinic)
Findings also showed that there was increased self-esteem, confidence and self-worth in those receiving CATS services.

“This intervention has done something magical for these adolescents. Now they have this confidence in them.”
(Nurse, Sesame Clinic)

Overall the study results confirmed programmatic experience. Those in the intervention had improved adherence; CATs helped motivate adherence and increase understanding of medication. The results confirmed the importance of home visits. The impact of the intervention was also felt by caregivers. Youth who had experiences of adherence issues and previous loss to follow up now found CATs links and reminders improved their retention in care. The intervention also showed improvements in psychosocial well-being, self-esteem, self-worth and confidence. Limitations of the study included the fact there were no objective measures, and anecdotal evidence of referrals was used.

The CATS model has now been scaled up to 36 districts of Zimbabwe under the Accelerated Action Plan for Treatment for Children and Adolescents, and is being implemented by the national MoH. Two randomized control trials are also soon to be conducted: 1) cluster randomized trial of the Zvandiri Programme, a multi-component, community-based programme to improve adherence and retention in care among children and adolescents living with HIV in Zimbabwe (MoHCC, CeSSHAR, ViiV Healthcare); and 2) the peer support intervention, which supports HIV-positive adolescents in Zimbabwe to improve HIV care continuum outcomes among adolescents with virological failure (MoHCC, UZCHS, JSI/USAID).

Audience question: It sounds like a great model. Who supports the CATS, do they get funding, how are they supported in delivering care, and what are the logistics of that?

Response: This cadre needs to be invested in and supported to work in balance with other community cadres. As evidenced by results, investment in CATS as a cheaper community-based intervention will be worthwhile. CATS are currently given a stipend for attending various training and support sessions, and we are trying to mobilize funding to get them more support. But we’re balancing that with the need to integrate this as a national model. This is being scaled up as a national model and they’re integrating into health facilities. But we’re working out how to support them in a way that is commensurate with other community cadres, and that’s a battle.

Presentation 3: PATA Promising Practice programme in the area of health worker sensitization though its REACH (Re-engage adolescents and children in HIV) and P2Z (Peers to Zero) programmes

Luann Hatane from Paediatric AIDS Treatment for Africa (PATA), South Africa, introduced the issue of facility-based stigma and discrimination faced by HIV-positive adolescents. She noted that adolescents have increasing mortality, have less access to treatment, present later to HIV services, have increased poor adherence and retention, and have specific psychosocial age-related transitions that compound their treatment outcomes. WHO commissioned PATA to conduct a situational analysis of HIV treatment and care services for adolescents. The PATA survey focused on 218 health facilities in 23 countries.

Findings from the survey showed that there are insufficient protocols to determine and manage non-adherence and loss to follow up. Adherence counselling generally focuses on adherence behaviour rather than the drivers of non-adherence, and there are limited mechanisms for peer support. Health workers attend to adolescents at the same time and in the same space as adults/paediatrics. There are limited or no protocols to guide the transition into adult services, and there is limited integration of and poor access to SRH services. There is insufficient data disaggregation and monitoring of outcomes, and insufficient access to viral load testing.

In the survey, health workers expressed varying degrees of stigma and judgmental attitudes towards HIV-positive youth.
“After delivery and after nursing her baby [she] should be left to re-unite with her fellow youth, but this time with caution not to mess up again but concentrate on studies.” (Doctor, Uganda)

“We should be counselling young people to abstain, and discourage YLHIV to be sexually active as they may pass HIV onto their child.” (Nurse, Malawi)

Adolescents report long waiting times, inconvenience and negative attitudes from health workers. Adolescents reported being denied services or provided with inferior services, being mistreated, shouted at, having their confidentiality breached and feeling coerced to undertake such services as sterilization.

PATA held a summit for peer supporters from seven countries, uniting the voices of young people, outlining their desires to receive respectful and sensitive adolescent-friendly services.

“My body, my treatment, my voice. You please advise and support.” (Youth summit)

“We request friendly and sensitized health care workers with positive attitudes and ask that HIV and SRH services be provided to us with care, acceptance, respect and without judgement. We should be provided with comprehensive information and recognized as capable of making our own decisions. Don’t lecture us, empower us!” (Youth summit)

ALHIV have the right to non-discrimination in health care. A rights-based approach is laid out in the 2030 Agenda for Sustainable Development (UNAIDS 2016-2021 Strategy). The WHO global strategy for human resources for health identified the sensitization of health workers as a crucial strategy towards improving an adolescent-friendly orientation and treatment outcomes. While a rights-based approach underpins the standards, principles and obligations setting out what the standards should be, in reality that is not the experience of young people accessing services. The challenge is how to shift policy into practise sensitize health workers and transformed facilities contribute to positive health outcomes for young people.

We must reach out to health care providers. Much of the discussion about health workers has to do with blame and shame, and often highlights negative aspects. It is also important to talk about successes, highlighting where we have seen results and shifting health provider responses. Health workers need to be motivated and inspired to create enabling environments so they can feel that they are central to the part of the HIV response.

In 2007, PATA initiated an expert patient programme, engaging the caregivers of young children as community health workers based in facilities. Those children grew up to become adolescents, and in 2015 PATA started the REACH adolescent project, engaging peer supporters based in a clinic for youth living with HIV. The most recent Peers to Zero component focuses on how young people increasingly need to be engaged in informing service delivery and be actively involved in the monitoring and evaluation of services that affect them.

There is no simple ‘one size fits all’ intervention in creating sensitized health workers, but it is critical to address the causes of stigma and discrimination. The drivers of stigma and discrimination by health providers include restrictive legislation and policy gaps, inclusive of laws relating to ages of consent, the criminalization of key populations, religious and cultural beliefs in the clinical space, misinformation and negative messaging. Health workers are often fearful and ill-prepared, faced with difficult situations, and lack confidence in dealing with difficult decisions and ethical dilemmas. They are also subject to power differentials and hierarchy in the health system and have limited means of redress. Most health facilities are under-resourced and over-burdened. Even when health workers are sensitized, many are working in desensitized environments.

Capacity building of health workers is not a once-off intervention; training must be part of on-going support. Champion health workers should be engaged in mentoring and providing peer-to-peer support. One method is the creation of simple WhatsApp groups for health workers to get support when faced with difficult situations. In addition, there must be greater accountability: what gets measured gets done. It is insufficient to just have the patients’ charter pinned on the wall; there must be more effective ways of measuring stigma in facilities, health worker attitudes and experiences of young people, such as through scorecards and patient dialogues. We need to move policy into practice in terms of leadership and management in our facilities.
PATA works to embed and situate young people at the centre of facilities. Peer supporters offer linkages and guide patients through processes, and also offer connection and proximity to health workers. This has shown to be an effective process to create dialogue and connection between young people and health workers, and to integrate young people into health facilities. It helps to better orient health workers to the needs of youth, in line with principles and values, so that health workers have greater understanding, are motivated, inspired and committed to work with young people.

**Audience comment:** Health workers also need a pat on the back; they work in resource-constrained settings. There are also misperceptions of what is really adolescent friendly.

**Response:** Yes, Absolutely. PATA hosts local and regional forums, bringing health workers and young people together. Methods, such as role plays, allow young people to express their realities, but also to allow health workers to do the same. We often don’t realise the challenges health workers face when working with young people, especially when faced with legal restrictions, limited time, tools and resources.

**Presentation 4: Beyond the clinic: The social basis of ART adherence among adolescence**

Lesley Gittings from the AIDS & Society Research Unit (ASRU), Centre for Social Science Research, University of Cape Town, South Africa, and Lucie Cluver from the Department of Social Policy and Intervention at Oxford University, England, presented findings in behalf of Rebecca Hodes (ASRU) and the Mzantsi Wakho (“Your South Africa”) study, which looked at the needs of adolescents in terms of their adherence to ARVs and sexual and reproductive health services.

The presentation was introduced by describing the context of global “treatment triumphalism” as being contrasted to the realities of mortality and morbidity among teenagers. Since 2000, the number of adolescent deaths from AIDS has tripled (WHO, 2015) and AIDS is the leading cause of death among adolescents (aged 11-19 years) in southern Africa. Of the 2.6 million children (age 0-15) living with HIV globally, 32% have initiated ART (UNAIDS, 2015). However, there are high rates of ART non-adherence (Hudelson and Cluver, 2015; Nachega et al, 2009).

**Figure 5:** Quantitative findings on non-adherence to ART (n=1060 HIV+ adolescents)
The Mzantsi Wakho study looked at adolescent needs on HIV/STI, using both quantitative and qualitative methods. The key research questions were: 1) what are the risks and protective factors for ART adherence and access to sexual and reproductive health services?; 2) what are the lived experiences of HIV-positive teens?; and 3) what can policy and programming learn from this?

Over a period of three years in the Eastern Cape province of South Africa, a range of youth, health workers and caregivers in urban, peri-urban and rural areas were interviewed. Methods included community tracing and three-year longitudinal tracking. The Eastern Cape is one of the most generalizable areas for other settings in eastern and southern Africa; it is the second poorest province in South Africa and has a provincial HIV prevalence of 11.6% (HSRC 2014). ART rollout is primarily nurse-managed.

The qualitative component of the study used participatory research, focus groups and workshops. It engaged 80 youth, 30 health care providers and 30 caregivers. In all, 36 months of community observations were conducted, as well as more than 1,000 hours of clinic observations (ART, family planning, trauma units). In addition, a quantitative longitudinal panel study was conducted: this was the largest community-based study of HIV-positive adolescents so far, involving 1,526 adolescents (1,060 HIV positive, 467 HIV negative), which was every adolescent who had initiated ART in a health district, from 53 health facilities.

The study baseline found past-week ART non-adherence was 36%, past-weekend non-adherence was 25%, and past-year inconsistent adherence was 52% (Cluver et al, 2015). The study found that a triumvirate of care (health care workers, caregivers, teens) is crucial in maintaining adherence. Findings showed that, generally, rates of self-reported non-adherence were much higher than expected. Self-reports vary in reliability, but these were checked against viral load and opportunistic infections. Despite some probable underreporting, non-adherence emerged as a very common problem.

Adherence goes beyond individual factors; clinical and social factors are also important. Various factors relating to clinical and socio-structural circumstances can help in enabling good adherence. Qualitative findings showed that with regards to caregiver and health care worker attention/surveillance findings showed that adherence is better when nurses and caregivers in clinics and homes pay attention. Adherence also improves when young people are at home a lot, and have a stable family with a highly routinized domestic life.
The results of an exercise for which youth were asked to depict their “dream clinic” showed that the physical clinic environment is important, including a comfortable waiting facility, nurses who very friendly and engaging, strong referrals, mobility, documents stored somewhere private and well-stocked pharmacies. Another exercise was a report card on adherence where adolescents rated different aspects of services, showing that teen voices can be brought to the forefront in policy making. Often services are rolled out according to checklists, however, these checklists and adolescent-friendly health services are often not meaningful.

Various structural factors impact on adherence, including the availability of food, the ability to imagine positive lives, and having hope. Among adolescents with no access to HIV support groups, no food security and low parental monitoring there was a 54% chance of non-adherence to ART in the past week. In contrast, amongst adolescents with all of these, there was only an 18% chance of non-adherence. The study found that food security was fairly high; however, parental monitoring was poor (42%) and rates of access to HIV support groups were very low (5%).

The study found non-adherence very complicated, that it is generally not deliberate and purposive, and that it is influenced by factors that are often “circumstantial”. These factors include: stock-outs; transport problems; food insecurity; physical home spaces that are crowded and lack privacy; high mobility and absence from home; difficult relationships with adult caregivers and partners; stigma; and status concealment. Adherence was negatively impacted by the side-effects of ART, including nausea, bad dreams, exhaustion, fatigue and lack of future ideation. Qualitative findings suggest that alongside social and structural factors, future ideation, well-being and physical appearance may be factors in ART adherence.

**CASH + CARE (+ CLINIC): LESS DEFAULTING**

Having experienced violence was a major factor impacting on adherence; the study found associations between exposure to violence and ART defaulting. Violence is a common feature of the environment, and comes in such forms as bullying and being attacked/robbed in the community; adolescents experience violence in an array of public and private settings, including those intended as sites of health and social service provision (e.g., schools and clinics). An adolescent who is beaten by their teacher or at home and experiences regular physical violence has a 66% chance of non-adherence in a week.

Beyond pill burden and palatability, medicines taking is a multi-sensory experience, and this may influence non-adherence: it includes smell, colour, coating, tastes, desires, and personal memories of medicine taking.

Medicines are experienced in a multi-sensory way, and this can influence non-adherence: it includes smell, colour, coating, tastes, desires, and personal memories of medicine taking.

One component of the Mzantsi Wakho project was “Yummy or Crummy”, a participatory research exercise aimed at capturing new ways of experience beyond pill burden and palatability, and allowing teens to report their experiences beyond conventional tools. “Yummy or Crummy” combined role playing with the preference-capturing visual strategies of social media. It involved the use of a report card to rate medication on such factors as consistency, taste, size and delivery method, and was piloted with 16 young people (9=female) living with HIV. They are part of Mzantsi Wakho’s Teen Advisory Group, a group of expert young participants with long-standing involvement in Mzantsi Wakho and related adolescent research projects. The “Yummy or Crummy” game expanded the conceptual parameters of ART adherence, with young people reporting on the multi-sensory dimensions of medicine-taking, including smell, colour, size, shape, clarity, effervescence, consistency, coating, packaging and delivery method. The exercise took the form of a game in which participants, role playing as chefs, visited different test stations and evaluated their preferences for taking medicines.

The findings demonstrated the importance of piloting new strategies to investigate and document medicine-taking as a multi-sensory experience among adolescents. Participants reported that that the taste, smell, size, colour and volume of medicines were all associated with adherence. Preferences for the smell, colour, consistency, taste, coating, packaging and delivery method of medicines were highly variable, related to individual participants’ experiences. Participants’ ideas about medicines were interrelated, with socio-structural and experiential factors playing a powerful role in reported preferences.
While ART adherence is often understood as a clinical experience, the “Yummy or Crummy” results highlighted the social dimension of medicine-taking, including:

- Socio-economic factors, such as the lack of a dependable supply of running water creating a preference for smaller pills that did not require liquid for swallowing
- Colours, tastes, consistencies and delivery mechanisms, which all had gendered significance
- Children and young people having particular needs regarding the smell, taste and delivery mechanism of medicines
- Medicine-taking being overlaid with emotion, with preferences highly contingent on previous experiences of illness and disease, both individual and familial
- Participants having a strong preference for medicines that they can easily identify, based on their colour, size, smell, taste and “scoring”.
- Participants preferred medicines that indicated that monitoring and regulation measures were in place, such as embossed numbers on the sides of pills.

The study demonstrated high rates of ART non-adherence and concluded that poor palatability and heavy pill burden are associated with ART non-adherence. But research on the multi-dimensional and multi-sensory experience of medicine-taking among adolescents remains scarce. Qualitative research indicates that non-adherence was associated with pills that tasted bitter, were large, were specific colours (related to unpleasant side-effects and to previous disease experienced, particularly TB), or exceeded a volume of two per day.

Findings showed that adherence has many elements, that current paediatric formulations of ART are often ill-suited to the needs of adolescents, and that enhancing the experience of medicine-taking is essential to improved adolescent ART adherence. Affected adolescent experiences and insights should be engaged using a multi-sensory approach that acknowledges the role of all the senses (not simply taste and volume). The study highlighted the need for innovative, “pansocio-clinical” programmes based on an eco-social model. Programmes must be responsive to adolescent needs and realities, spanning and incorporating social and clinical worlds, and tapping into the resilience of young people and using it to promote positive health-seeking behaviours.

**Presentation 5: Transition of Thai HIV-infected adolescents to adult HIV care: Peer interactions and peer support for positive health outcomes**

Annette Sohn from TREAT Asia/amfAR presented on models that have been used to support transitioning adolescents in Thailand. She described the differences between the HIV epidemics in Thailand and sub-Saharan Africa. In Thailand, there are less than 450,000 people living with HIV. Approximately 150,000 of those are under 25 years of age, and two-thirds are men having sex with men (MSM). The newest infections are most frequently among young MSM.

Thailand initiated a “treat all” policy from October 2014 ahead of WHO recommendations, and offers universal health coverage. Successes in their efforts to control the epidemic include the elimination of MTCT of HIV and congenital syphilis by June 2016; in 2014, there were only 121 new paediatric infections. Thailand can see an end to AIDS by 2030. However, stigma remains a huge issue and barrier to that goal, despite the country’s other successes.

There is a national paediatric clinic/hospital network, and most adolescent care is delivered in specialist paediatric HIV clinics. However, there are increasing infections among young MSM who may not benefit from this type of clinic structure; MSM don’t fit in the paediatric clinic as they are generally older and their infections are related to high-risk behaviors occurring later in life, rather than through perinatal infection. This leads to different medical and social needs.

Thailand has formal transition guidelines and special programmes at the referral level, including Happy Teen*, CHAMP+ and youth and transition camps. Thai paediatric programmes have focused on peer interactions and support, working with young people and facilitating their transition into adult life. Peer support is essential for improving clinical outcomes. In order to attain viral suppression and retention in care, many other needs must be met, including relationships, family communications, and access to care.
Young people, regardless of HIV status, have a diversity of needs and preferences, in terms of where support comes from, and the kind of services they want. Some young people want to attend support groups and activities, some never want to go. Some people find adherence easy; others find it much harder. One common theme is that youth trust other youth. Young PLHIV are tired of adhering to ART, but it is harder for health workers to understand this. They want to talk to other youth who understand their situation.

In addition, the fear of stigma drives the need for peer support and impacts adherence. In the setting of a smaller national epidemic, the general population has less knowledge about and awareness of HIV, which increases stigmatization. Young people feel unable to disclose their status, which creates a sense of isolation, and in turn impacts their desire to take medication. This increases the value of youth-focused programmes as these are frequently the only places that young people find acceptance of their HIV status and where they feel able to disclose.

In terms of engagement methods, the use of mobile devices in Thailand is massive: on average, there are 1.5 mobile devices per man, woman, and child. Youth do not want to disclose their HIV status on social media, but they do use other messaging media to connect to health worker and peer support. This heightens the value of youth programmes, including social media platforms, as well as face-to-face workshops and camps with other PLHIV youth. In these spaces, young people can feel safe and find acceptance and relief from keeping “secrets”. Using art and other modalities, young people share their hopes for the future and become each other’s role models. These camps give young people the opportunity to be openly HIV positive in a private, safe space. Health workers can also engage and connect with youth in these spaces, helping build rapport and relationships. Integrating “graduating” young adults – peers who have passed through adolescence and stayed in or returned to care – into HIV clinical programmes as role models demonstrates trust and builds leadership.

Some of the Thai transition programmes have been able to create multidisciplinary support for a formalized hand-over process from pediatric to adult care. An effort is made to link paediatric and adult providers to each other to directly communicate about an individualized plan for the patient. This includes promoting greater acceptance of HIV as a chronic illness and focusing on future goals, including adherence for long-term survival. Youth learn the skills needed to negotiate appointments with multiple providers in an adult practice setting, and set educational and employment goals. The intent is to help them to achieve independence, assume responsibility for their treatment, and participate in decision-making. Providers prioritize helping youth to receive uninterrupted comprehensive medical care, but efforts are made to meet psychosocial support needs, which may include arranging for housing, health insurance, and transportation.

In conclusion, by working with providers and youth in support of youth, Thailand’s paediatric HIV programmes and national transition guidelines have facilitated the development of special programmes for transition of YLHIV to adult life. Peer support is essential and can improve clinical and programme outcomes during critical time periods. Youth workshops and camps can create open spaces for sharing, encouragement and mentorship. Fear of stigma and disclosure, however, continue to be the main barriers to successful life-long care.
Linda-Gail Bekker from the Desmond Tutu HIV Centre, South Africa, presented on innovative youth programmes. The context is that many young people do not test for HIV, and linkage to care is problematic; youth need services that connect with them. Young women are better than men at testing, but mostly through antenatal care. Health care must be more technically advanced. South Africa had a huge national testing programme, and there have been improvements, but getting youth to test is still a struggle. Global data show that youth are reticent to test, especially younger adolescents who are not accessing antenatal or SRH services. We need to teach that testing is normal: it must become a way of life.

How do we achieve that in an environment where most clinics are not youth friendly? It is important to take into account the socio-ecological context that adolescents live in. Barriers to young people accessing services include personal barriers, such as discrepancies between sexual debut and psychological maturity. Societal, cultural and religious barriers include the “compassion conundrum” with health workers providing compassion only once a teenager is pregnant or HIV positive, but there is a lack of engagement in provision of resources to healthy young people.

Youth centres provide comprehensive services, including recreation and education, with clinical services at the core. To further extend services to young people, the Tutu Teen Truck, “health on wheels”, was developed; this is intended to de-stigmatize HIV testing and take HCT to the most at-risk and resource-limited communities. The truck uses biometric fingerprint registration, which means that no names are needed. Services include incentivized testing and treatment for couples, rapid HIV testing, CD4 counts, viral load testing, ART, PrEP, contraception and pregnancy screening, “sexy” condoms, STI screening, and basic primary care, including BMI, blood sugar and mental health screens. There is a trusted referral system, with good relationships with primary health care. Text messages are used to improve LTC and health behaviours; social media platforms are also used, providing interactive information. The truck is a point of care (mental health, internet, career planning).

The project runs health education quizzes with prizes. Services are provided at times and spaces convenient to youth, in a friendly, non-judgmental, accessible manner. Youth are incentivized to use the trucks HIV services by other services that are being offered at the same time such as CV writing, music, WIFI, hair braiding and manicures.

At least 30-40 kids are tested in the vehicle per day. Many test negative, and there have been increases in the number of young men, with about half testing for the first time. Adolescents accessing the truck display some risky HIV-related behaviour, which suggests that PrEP availability could be a valuable. Shortly, same-day PrEP for adolescents will be provided, and support groups and adherence clubs will be set up for both HIV-positive and HIV-negative young people.
The Tutu Teen Truck has also been testing an HIV self-testing device among adolescents. The kit is self-initiated and easy to use, and it is impossible to make a wrong assessment. Usability and viability of the kit has been assessed. On the whole, young people have accepted it, rated usability highly, enjoyed using it, and had good correlation with counsellors. Youth expressed a high preference for self-testing (74.9%) over traditional HCT.

In conclusion, youth-friendly services need us to “think outside the box”. Key aspects are convenience, ease of use, tailored services and making use of technology. Youth-friendly services must be adolescent centred rather than issue centred, and should bundle age-appropriate interventions and use strong linkages that already exist. There must be a greater focus on tailored combination HIV prevention for adolescents, incorporating structural, biomedical and behavioural interventions within a rights and privacy framework. Adolescents want tailored information and services, privacy and confidentiality, and trustworthy connections. Prevention and treatment must be combined to meet the needs of adolescents. Services must be community based, with community partnerships. Importantly, they must be non-judgmental, integrated and include greater staff continuity. They should have flexible opening hours, be affordable, have greater peer involvement, have a relaxed environment, have better psychosocial support, and have other services available. In summary, services must be accessible, efficient, friendly, tailored, funky and comprehensive.

Presentation 7: PEPFAR perspective

George Siberry, from the Office of the U.S. Global AIDS Coordinator (S/GAC), U.S. Department of State, United States, contributed PEPFAR’s perspective to the discussion.

1. Self-testing holds an incredible promise of improving the reach to at-risk youth by making testing more acceptable and accessible. A study in Malawi showed that 16-19 year olds had the highest levels of self-testing and have very good linkage rates. Findings like these allow us to encourage self-testing programmes. However, self-testing kits need government approval and must be of good quality and safe. This may lead to barriers and delays, but these programmes look like they will work well.

2. Youth-friendly services: It seems that if services are to be friendly to youth, they have to be good. But we need to understand what this actually means and what makes services friendly and at the same time empowering for adolescents. Studies on impact are inconsistent. It is not enough to say that services are “youth friendly”; we need to also understand the specific components that make a difference.

3. Adolescent peer support models have demonstrated outcomes of improving retention, improving virological suppression, and resulting in good psychosocial well-being. This gives us the motivation to encourage the introduction of these models and scale up elsewhere. Evidence helps us know what to invest in. Sustainability is important. PEPFAR’s OVC programmes, which include services like social protection and investments in education and which may have been historically more directed to younger children, can have tremendous value for adolescents and youth as well. These resources can be leveraged for older youth.
Questions from the audience

**Question 1:** How and who is responsible for bringing about impact and change? Who should be taking care of all of these needs, such as social protection, sexual violence, food security, housing, financing for their livelihoods, and hygiene needs? Who should be responsible for these?

Rachel Vreeman responded by saying that this is an important and challenging issue, that there are multiple layers of support, and that it is critical to look at the impact of caregivers on the health of adolescents. There is a need to strengthen community and government partnerships in order to address different aspects, including food security, support networks and school environment.

Nicola Willis added that this cannot all be done by the health sector. There is a need to work with communities to identify pressing social issues, partnering with child protection services and social welfare, as well as the health sector. In this way, there can be an identification of home issues and sensitive case management, which would strengthen support for those cases.

Annette Sohn added that it is a public health responsibility of a country to its people. Governments need to invest time and resources in public health programmes. It is critical to focus on adolescent hotspots and provide intensified care for adolescents. Young people are in a high-risk period of their lives.

**Question 2:** In the context of rights-based access to care, how do you deal with situations in which what adolescents want or do is in direct conflict with what is culturally and legally acceptable and what law and policy makers will agree to do, for example, lowering the age of consent? How do we work within restrictive legal and policy environments?

Annette Sohn responded by saying that issues, such as the age of consent and criminalization of sex work, drug use and homosexuality, must be treated as policy and advocacy priorities. This is a major advocacy area. Experts need to bridge the gap and young people themselves need to be part of these efforts.

**Question 3:** How should the worry that adolescents have about their futures be dealt with in terms of future prevention and resilience building?

Janet Bhila responded by saying that it is critical to address treatment literacy, for example, in body changes related to ARVs. Peer-to-peer support is also vital, as is counselling and teaching adolescents to communicate their concerns so we can attempt to understand adolescents' lived experiences.

Nicola Willis added that support groups are central. HIV-positive young people feel different from their friends and peers. Stigma and depression are correlated with poor adherence. Support groups are important; we can’t underestimate the value of getting youth together in a safe space, with other young people who they can identify with and who share the same physical characteristics. This creates a sense of belonging and enables young people to share coping strategies and learn from each other. Retention and support groups go hand in hand, as do early disclosure and adherence. There is a need to link psychosocial aspects with clinical outcomes like retention and virological suppression.
SESSION DESCRIPTION:
Reducing new infections and AIDS-related deaths among adolescents is a key component of the global plan to end the AIDS epidemic by 2030. The Satellite will provide a platform for researchers, healthcare professionals and programme implementers to discuss promising clinical care practices for adolescents, to assess replicability in different contexts, and to identify options for adaptation, where required. The symposium is thus designed to both strengthen the evidence base through presentation of new research on adolescent HIV services, and to help address key gaps in adolescent HIV prevention and care by improving knowledge among practitioners of targeted approaches. The specific learning objectives are to understand a) strengths and weaknesses of different models of clinical care and how this affects the prevention, care and treatment outcomes for adolescents, b) how HIV care services are experienced by adolescents living with HIV and what kind of support they need, and c) how HIV services and health care professionals can support the optimization of clinical care delivery.

The scientific program of this Satellite has been reviewed by the American Medical Association and approved for a maximum of 2.0 AMA PRA Category 1 Credits™.

CO-CHAIRS:
Rachel Vreeman, Indiana University, United States
Carlo André Oliveras Rodriguez, Adolescent HIV Treatment Coalition, Puerto Rico

PRESENTATION TITLES AND SPEAKERS:
1. “Taking them forever and taking them on time”: The treatment and care needs of adolescents living with HIV
   Speaker: Janet Bhila, Global Network of Young People Living with HIV (Y+), Zimbabwe
2. Zvandiri CATS model: Findings from a community peer support treatment intervention in Zimbabwe
   Speaker: Nicola Willis, Africaid Zvandiri Harare, Zimbabwe
3. Health worker sensitization: Promising practices from PATA’s REACH and Peers2Zero programmes
   Speaker: Luann Hatane, PATA, South Africa
4. Beyond the clinic: The social basis of ART adherence among adolescents
   Speakers: Lucie Cluver, University of Cape Town, South Africa and Lesley Gittings, Centre for Social Science Research, South Africa
5. Transition of Thai HIV-infected adolescents to adult HIV care: Peer interactions and peer support for positive health outcomes
   Speaker: Annette Sohn, TREAT Asia/amfAR – The Foundation for AIDS Research, Thailand
6. Community-based HTC and self-testing: uptake of mobile clinics (teen truck) and HIV self-testing devices among adolescents in South Africa
   Speaker: Linda-Gail Bekker, Desmond Tutu HIV Centre, South Africa
7. Discussant presenting PEPFAR perspective
   Speaker: George Siberry, Office of the U.S. Global AIDS Coordinator (S/GAC) U.S. Department of State, United States