Mmata Tswana is a project of Scottish Livingstone Hospital in Molepolole, Botswana. Community caregiver support groups consist of caregivers of ALHIV. The core aim of these groups is to support adherence, retention in care and health outcomes in ALHIV.

The Mmata Tswana model is a Community caregiver support group model which offers an opportunity for caregivers to:

- Meet, discuss and learn from one another about ART adherence and caring for ALHIV;
- Provide psychosocial to one another;
- Offer general care-giving support to one another by, for example accompanying each other’s children for scheduled appointments, as well as assist them with treatment as necessary; and
- Create a community of knowledge about adolescents’ treatment and health needs to minimize the risks associated with loss to follow-up when a caregiver is unable to take care of an adolescent. For example, if a caregiver becomes ill, other caregivers in the group can step in to provide support based on their knowledge of the child’s health needs.

Mmata Tswana was developed in response to poor adherence and retention in care amongst adolescents living with HIV (ALHIV) attending Scottish Livingstone Hospital. Various factors beyond the control of the caregiver and ALHIV influence the availability of one primary caregiver to consistently accompany the adolescent to clinic visits or actively engage in their care and treatment. These range from work commitments, household instability, illness and even death.

Health workers at Scottish Livingstone Hospital observed that such caregiver inconsistencies and poor engagement influenced loss to follow up and non-adherence to ART by ALHIV.

Mmata Tswana is based on the premise that when caregivers themselves are given support, both psychosocial and practical, they are better equipped to assist and encourage adherence to treatment in adolescents, and to ensure that they are accompanied to scheduled clinic appointments.
BACKGROUND

In 2014, 2.6 million children were living with HIV. Children are a third less likely to receive treatment than adults, with less than one in three (32%) accessing ART in 2014. Coverage is lowest in sub-Saharan Africa, which accounts for 90% of the global paediatric need. HIV-related paediatric mortality is staggering, with 150,000 children dying of AIDS-related causes in 2014 alone. HIV-related deaths have decreased in all other population groups since 2000, while tripling among adolescents in the same period. AIDS is now the leading cause of death among adolescents in Africa, and the second cause of death among adolescents globally. It is becoming increasingly apparent that adolescents are underserved by existing HIV services, with significantly worse access to ART than adults, with lower rates of adherence, virological suppression and immunological recovery.

Overburdened clinic teams are often unable to offer the psychosocial support and child- and/or adolescent-friendly services that are needed to provide holistic, integrated and comprehensive care to young people. Caregivers also face challenges in supporting children’s adherence to ART such as poor comprehension of complex treatment regimens and distance and travel costs to health facilities. Factors such as caregiver age, deteriorating memory and physical immobility can also impede children and adolescent access to monthly clinic visits and hence adherence.

HIV-positive children and adolescents face various challenges including disclosure, adherence, cognitive delays and clinical conditions. Even when access to treatment and adherence support is in place, complex social issues such as stigma, psychological distress and fear, family conflict and caregiver challenges contribute negatively to the health of

It is becoming increasingly apparent that adolescents are underserved by existing HIV services, with significantly worse access to ART than adults, with lower rates of adherence, virological suppression and immunological recovery.
HIV-positive children and adolescents. Poverty and household illness reduce the resilience of HIV-affected families to cope with livelihood stressors and disease burden.

It is suggested that certain combinations of interventions, as well as a targeted approach, should be used to effectively address HIV-positive children and adolescents’ unique needs. Young people living with HIV require specialized and multifaceted support from health providers and communities to remain in care. Given the complexity of HIV treatment and adherence, children and adolescents require support from caregivers and community members. As experts in their own situations and children’s closest supporters, caregivers are crucial to providing psychosocial, adherence and retention support to the children and adolescents that they care for. They are well placed to provide overall health support, including with adherence, disclosing to them in an age-appropriate way, addressing stigma and supporting sexual and reproductive health. In order to provide support to the children and adolescents that they care for, caregivers often require support themselves.

Additionally, evidence suggests that improving community competence about ART adherence can support adherence for children living with HIV.

Drawing from this, Mmata Tswana works to provide integrated adolescent-caregiver support with the aim of improve ART adherence and retention in care amongst ALHIV and community ART competence.

**OBJECTIVE**

Mmata Tswana is a community caregiver support group programme that aims to:

- Improve caregiver visit accompaniment;
- Support ART adherence in ALHIV;
- Ensure that adolescents are retained in care;
- Enhance relationships and connections between caregivers and ALHIV; and
- Create a network of support for caregivers living in the same community;

**IMPLEMENTATION STRATEGIES**

**Adolescent-caregiver pairs**

Community caregiver support group members are each the caregiver of an ALHIV who has been initiated onto treatment and disclosed to at Scottish Livingstone Hospital. This caregiver support group is unique in that it is focused on adolescent health outcomes, and not solely on supporting the caregiver support group members.

**Mixed adherence groups**

Community caregiver support groups consist of caregivers of ALHIV adhering well to treatment and caregivers of ALHIV not adhering to treatment. The aim of this mixed adherence support group is to provide opportunities for information sharing, motivation and support amongst caregivers. Groups are small (between 4-5 caregivers), in order to create an environment in which caregivers feel open and comfortable, and also so that members do not feel overburdened by for example, accompanying multiple children to the clinic.

* An ‘adherence-competent community’ is defined as ‘those social relations that enable and support the likelihood of optimal adherence despite poverty and social disruption’ (Campbell et al 2012).
Identification

Given that the project aims to bring caregivers of ALHIV with varying levels of adherence together, potential adolescent-caregiver pairs are identified based on the clinic’s categories/definitions of adherence and treatment failure. ALHIV are also required to be fully disclosed to in order to be eligible for the project.

Recruitment & Enrollment

Caregivers of eligible ALHIV are contacted about the project, and if they are interested to learn more, they are invited to come to the hospital for a one-on-one appointment with involved hospital staff. At the appointment, interest is secured, and upon giving consent, baseline data is collected.

Data

Demographic information is collected about the caregiver and adolescent. For caregivers, this includes the following:
• Age
• Gender
• Type, for example, grandmother

For ALHIV this includes:
• Age
• Gender
• Whether the child is school-going or not
• Viral load
• CD4 count
• History of adherence to scheduled appointments.

Grouping

Groups are formed based on the location and adolescent adherence level.

• Location: Caregivers are grouped together based on community location. The objective here is that caregivers in close proximity can attend meetings and support each other more easily.

• Level of adherence: Groups consist of caregivers of adolescents with high and low levels of adherence so that they can learn from and support one another.
Orientation

An orientation meeting is used to bring together all adolescent-caregiver pairs enrolled in the project. In the meeting:

1. Participants are introduced and oriented to the programme and the community health worker who will be working on and helping implement the project. They are also familiarised with the overall project plan.

2. Adolescents and caregivers are introduced to their community caregiver support group, and decide on an informal leader who spearheads the group’s activities.

3. Potential ways in which group members might support each other are shared, including:
   » Sharing adherence support experiences;
   » Meeting regularly to discuss challenges and solve problems together;
   » Bringing other caregiver’s children to appointments;
   » Sharing details about adolescent treatment and health needs so that other caregivers can step in to provide support if the primary caregiver is unable; and
   » Providing childcare support to one another.

4. Community caregiver support group discussions are held around which support mechanisms the group think might work best for them.

5. Materials are shared about adherence, attending hospital appointments, care-giving, teamwork, communication and retention.

Meaningful involvement of People Living with HIV

A key intervention strategy in line with international best practice is the meaningful involvement of people living with HIV (PLHIV). An HIV-positive community health worker (CHW) is involved in the project to conduct home visits and provide group support, and is provided a stipend, in acknowledgement of their expertise and work.

Home visits

Once participants are enrolled in the project and attend the orientation meeting, the Mmata Tswana community healthcare worker conducts individual home visits to perform a situation analysis. The analysis makes use of a simple questionnaire to better understand the challenges or factors that the ALHIV face that affect adherence, such as school performance, general health status, and food security for example. Additional home visit activities include motivational talks and onward referrals where necessary.

Group support

The Mmata Tswana CHW conducts monthly visits to each community support group to provide technical support and ensure a linkage to the clinic. The CHW facilitates a discussion about what the support group has been doing, what support they have been providing to each other (e.g. psychosocial, clinic attendance, child care), what has worked and what has not, and what additional support they need.
PROGRESS TO-DATE

The Mmata Tswana model is in early phases of implementation. As such, results, successes, challenges and lessons learnt are not yet available in full. However, a preliminary review of implementation to-date reveals promising results. These include:

- Significantly more adolescents were accompanied by caregivers to scheduled appointments; only one adolescent was reported as showing up at the clinic unattended.

- Significantly increased adolescent adherence to laboratory appointments.

- Improved ART adherence amongst ALHIV. Of the 8 ALHIV with unsuppressed viral loads originally enrolled in the project, 5 are now fully suppressed.

- Reduced burden on hospital staff due to task-shifting of home visits and group support to CHW.

- Stronger patient linkages with the hospital facilitated by the CHW.

Preliminary challenges included:

- Although participants were grouped based on their community location, they are nonetheless required to travel in order to meet up with their support group. Caregivers often lack funds to attend the support group.

- Some caregivers have lost interest and have not attended meetings after the initial home visit.

- Many participants require additional support beyond what the support group can provide. Other factors impede ART adherence and clinic attendance such as food insecurity, illness and psychosocial needs, and these cannot always be addressed by the clinic due to inadequate resources.
• Shortages in medical staff means that ALHIV do not always receive their required tests to measure viral load and CD4, despite attending scheduled appointments accompanied.

• Some participants have been unable to participate due to personal issues, or because of changing home environments and caregivers.

• Inadequate stocking and maintenance of testing equipment meant that the implementers could not consistently measure programme impact.

• Volunteer community health worker and clinic staff workload, expectations and commitments may be difficult to manage, which can impede project implementation.

• Inadequate knowledge at the clinic about adolescent circumstances such as home environments can affect attendance and adherence.

Preliminary reviews of Mmata Tswana implementation to-date reveals promising results on adolescent adherence and caregiver involvement.
Scottish Livingstone Hospital’s Mmata Tswana community caregiver support group project is a unique and promising model. Creating networks of support for caregivers to help adolescents living with HIV to adhere to ART and hospital visits has the potential to improve adolescent health outcomes while reducing caregiver burden. Such a model, whilst initiated through the clinic, could also provide an opportunity for clinic and local community-based organizations to collaborate and ensure that caregivers are provided with consistent support and coordination beyond the limitations of services that can be provided by health facilities. Despite having the potential for immensely positive impacts on caregiver and adolescent well-being, psychosocial models, such as Mmata Tswana may also require significant time investments and consistent coordination and support. Despite being a novel and promising model, further monitoring is required to determine its efficacy.

Resources & links

- S2S, Psychosocial & Adherence Counselling Support Training Toolkit, 2010. (http://sun025.sun.ac.za/portal/page/portal/South_to_South/Apstools)
- Museum of AIDS in Africa. (http://museumofaidsinafrica.org)
- Avert, 2015 (www.avert.org)
ENDNOTES


2 Ibid

3 Ibid


5 Ibid


22 Ibid.

For more information:

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