



PROMISING PRACTICES

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 adolescents living with HIV (ALHIV);
- Provide psychosocial support 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 assisting them with treatment as necessary; and
- Create a community of knowledge about adolescents' treatment and health needs to minimise the risks associated with loss to follow-up when a caregiver is unable to take care of an adolescent.

Mmata Tswana (My Partner)

Community caregiver support groups to improve ART adherence amongst adolescents living with HIV



Molepolole, Botswana

Mmata Tswana is a community caregiver support group project of Scottish Livingstone Hospital. The core aim of Mmata Tswana is to support adherence, retention in care and health outcomes of adolescents living with HIV (ALHIV). Groups are made up of caregivers of ALHIV that have been initiated onto treatment at Scottish Livingstone Hospital in Molepolole, Botswana.

Molepolole is a peri-urban village with a population of approximately 70,000 inhabitants. It is located 50 kilometres west of the capital of Gaborone. Scottish Livingstone Hospital is the only health facility that provides HIV treatment services in the area. The next closest health facility is a primary hospital 40 kilometres south of Molepolole. For this reason, many people, including ALHIV and their caregivers, travel long distances to access the services they need.

Mmata Tswana was developed in response to poor adherence and retention in care amongst adolescents living with HIV (ALHIV) attending Scottish Livingstone Hospital. There are various factors that influence the ability of the caregiver to accompany the adolescent to the clinic and be actively engaged in their care and treatment. These range from work commitments, distance to the



health facility, household instability and poor emotional and physical wellbeing. Health workers at Scottish Livingstone Hospital observed that caregiver inconsistencies and poor engagement negatively influenced ALHIV retention and ART adherence.

Mmata Tswana is based on the premise that when caregivers are given psychosocial and practical support, they are better equipped to assist adolescents in adhering to treatment and care, including accompaniment to scheduled clinic appointments.

BACKGROUND

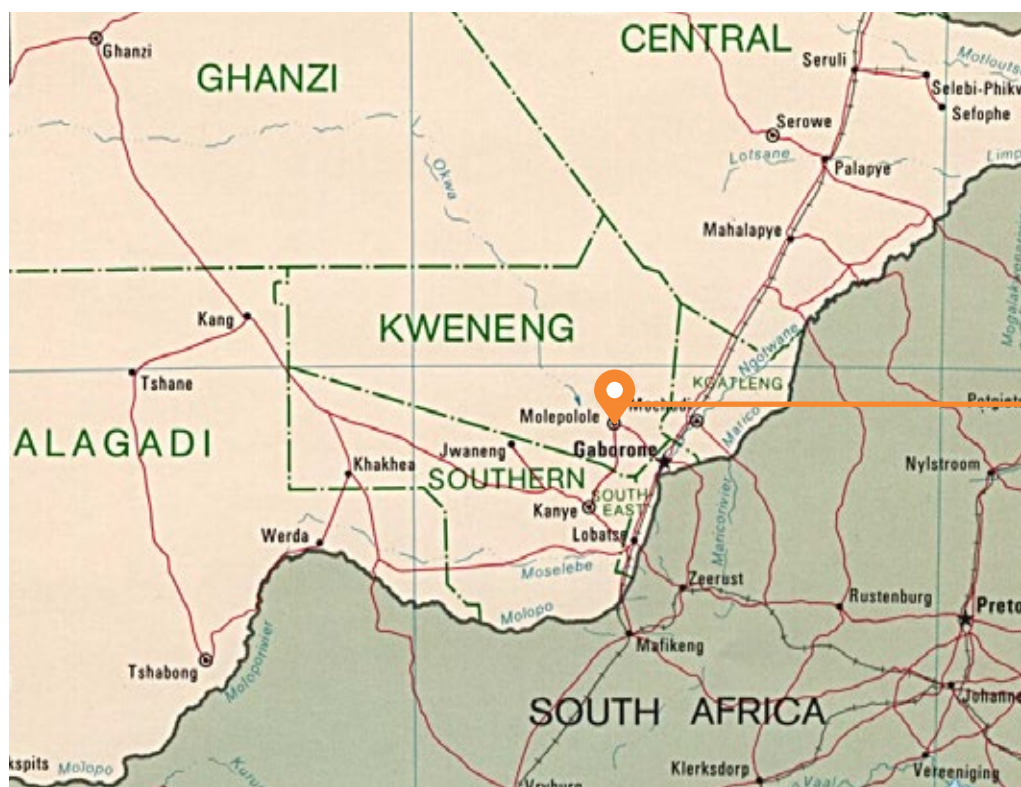
The majority of the world's adolescents with HIV live in Eastern and Southern Africa (ESA)¹. AIDS-related illness is the leading cause of death among adolescents (ages 10-19) in this region, and the second amongst adolescents globally². Since the year 2000, the number of AIDS-related

deaths amongst adolescents in ESA has tripled, while declining in all other groups².

Botswana has one of the world's highest HIV prevalence rates, estimated at 18.5% of the population over the age of 18 months³. Adolescent HIV prevalence in Botswana is higher than in many other countries in the region, with an estimated 4.74% of the adolescent population infected.

In Botswana, as in other countries in ESA, adolescents are underserved by existing HIV services. They have significantly poorer access to antiretroviral therapy (ART) than adults do, lower rates of adherence, virological suppression and immunological recovery^{4,5}. Adherence to ART is required for virological suppression, reduced mortality and immunological recovery⁶⁻⁹. Clinically, regular and comprehensive monitoring of growth and development, CD4 count and viral load are fundamental aspects of quality adolescent

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Molepolole
Mmata Tswana is a project of Scottish Livingstone Hospital in Molepolole, Botswana

HIV care and treatment and successful clinical outcomes^{7-9,29,30}. In Botswana, paediatric and adolescent sites that focus on detection of early ART non-adherence have demonstrated substantially better outcomes, making a strong case for such interventions^{7,10}.

Like in many other settings, it is uncommon in Botswana to speak openly about HIV and AIDS: secrecy, stigma, discrimination and isolation have been documented as major impediments to wellbeing and adherence of adolescents living with HIV^{11,12}. Other documented barriers include disturbances in neurocognitive development, violence, poverty and psychosocial issues¹²⁻¹⁵.

Family-level risk factors for adolescent non-adherence to ART include disrupted family structures and caregiver-child relationships, non-disclosure of HIV-positive status to the child by an appropriate age and family conflict¹⁶⁻²⁵. Caregiver challenges in supporting adolescent adherence to ART include that they themselves may have poor comprehension of complex treatment regimens, physical illness and psychosocial challenges. Distance and travel costs to health facilities and caregiver physical immobility can also impede adolescent access to monthly health

facility visits and hence adherence²⁶⁻²⁸.

Even when adolescents can get to the health facility, overburdened health service teams are often unable to offer the psychosocial support and services that are needed to provide holistic, integrated and comprehensive care to young people.

Given these complex challenges, young people living with HIV require specialised and multifaceted support from health providers, caregivers and communities to remain in care^{4,6,31}. It has been suggested that certain combinations of social protection interventions^{32,33}, including those focusing on caregiving, such as good parental monitoring and health facility support, can assist with ART adherence and effectively address HIV-positive adolescents' unique needs.

Caregiver wellbeing is crucial for the provision of psychosocial, adherence and retention in care support to the adolescents that they care for³⁴⁻³⁷. Family support, interactions with other adolescents living with HIV, and extensive support networks have been found to buffer some of the challenges that adolescents living with HIV in Botswana face in adhering to ART and to strengthen positive coping mechanisms³⁸⁻⁴³. Evidence

“Caregivers are the biggest supporters of taking pills, nutrition and living positively.”³⁵

- Lynette Mudekunye (REPPSI)



Groups are small (between 4-5 caregivers), in order to create an environment in which caregivers feel open and comfortable, and so that members do not feel overburdened.

from Botswana also suggests that accessing social support, strong relationships with family and caregiver openness in relationship to their HIV-positive status are related with adolescents being able to cope positively with stressors in life⁴¹. A recent review of initiatives in Botswana also noted the importance of health workers supporting caregivers with the skills and techniques they need to support adolescent adherence to ART⁴⁴. In acknowledgement of weak government service linkages, Botswana has seen a recent impetus for family-centred strategies for the provision of protection, care and support for vulnerable young people⁴⁴. There is a clear need for innovative programmatic responses to support adherence to ART and health facility appointments amongst adolescents living with HIV.

Mmata Tswana recognises the expertise of caregivers as supporters of adolescents.

They are well placed to provide adherence support, age-appropriate disclosure and address stigma³⁵. In addition, evidence suggests that improving community competence about ART can support adolescent adherence²². Drawing from this, Mmata Tswana works to provide integrated adolescent-caregiver support with the aim of improving ART adherence and retention in care amongst ALHIV.

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 each care for an ALHIV who has been initiated onto treatment and disclosed to at Scottish Livingstone Hospital. The objectives of this caregiver support group are two-fold: (1) improving ALHIV health outcomes; and (2) supporting caregiver wellbeing.

Mixed adherence groups

Community caregiver support groups consist of caregivers of ALHIV with mixed adherence outcomes. 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 so that members do not feel overburdened.

Identification

ALHIV are required to be fully disclosed to in order to be eligible for the project. The project brings together caregivers of ALHIV with varying levels of adherence. Potential adolescent-caregiver pairs are identified based on the clinic's categories/definitions of adherence and treatment failure.

Recruitment & Enrolment

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
- Caregiver relationship to adolescent (e.g. grandmother).

For ALHIV this includes:

- Age
- Gender
- School enrolment
- Viral load
- CD4 count
- History of adherence to scheduled appointments.

Grouping

Groups are formed based on:

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

A meeting is held to bring together all adolescent-caregiver pairs and orient them to the project. In the meeting:

“Caregivers need support before they can give it: If they are depressed they will give depression. If they are angry they will give anger. If they are well within themselves, they will give wellness...(and) can develop strong relationships with those they are caring for which will improve the physical health of both.”³⁵

- Lynette Mudekunya (REPPSI)

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 discussed, and may include:
 - 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 provide support if the primary caregiver is unable; and
 - Providing childcare support to one another.
4. Information and written materials are shared about adherence, attending hospital appointments, caregiving, teamwork, communication and retention.

Community Health Worker

A key intervention strategy of the project is to involve a community health worker (CHW). As a person living with HIV, the CHW shares their experiences and knowledge of adherence, caregiving and the health system. The CHW is provided a monthly stipend to conduct home visits and provide group support.

“We engage with caregivers so we can know challenges facing and find solutions. We engage with them so can appreciate them³⁵”.

- Lynette Mudekunye (REPPSI)



Home visits

Once participants are enrolled in the project and attend the orientation meeting, the Mmata Tswana CHW 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 affecting adherence, such as school performance, general health status, and food security. 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 linkages with 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, challenges and additional support needed.



Significantly more adolescents were accompanied by caregivers to scheduled appointments.

PROGRESS TO-DATE

The Mmata Tswana model is in early phases of implementation and the sample size is small. 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. 62.5% of the ALHIV with unsuppressed viral loads enrolled in the project are now 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.
- Despite attending scheduled appointments accompanied, shortages in medical staff mean that ALHIV do not always receive their required tests to measure viral load and CD4.
- 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 mean that the implementers can not consistently measure programme impact.
- Expectations and commitments with regards to workload, responsibilities and communication have required substantial management.
- Staff are often unaware of adolescent circumstances (e.g. home environments) that may affect their attendance and adherence.

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.

CONCLUSION

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 organisations to

collaborate and ensure that caregivers are provided with consistent support and coordination beyond the limitations of healthcare services. Despite having the positive potential for caregiver and adolescent well-being, psychosocial models such as Mmata Tswana may also require significant time investments and consistent coordination and support. To determine its efficacy, this novel and promising model requires further monitoring.

Getting to know PATA

Our MISSION is to mobilise and strengthen a network of frontline healthcare providers to improve paediatric and adolescent HIV prevention, treatment, care and support in sub-Saharan Africa.

Our VISION is that all children and adolescents living with HIV in sub-Saharan Africa receive optimal treatment, care and support and live long, healthy lives.

PATA's objectives are:

1. To improve the quality of paediatric and adolescent treatment, care and support at health facility level
2. To grow and deepen engagement of the PATA network and increase peer-to-peer exchange between health providers across countries and regions
3. To incubate, document and share promising practices in paediatric and adolescent treatment, care and support in order to effect positive change in policies, programmes and practices at national and global levels

PATA works through four activity streams: PATA Forums, PATA Incubation Projects & Programmes, PATA Practice-Based Evidence & Advocacy and PATA Connect.

PATA Promising Practices

Find out more about PATA's work by reading the other briefs in this series:

1. **Project REACH: Re-engaging adolescents and children in HIV treatment and care**
http://www.teampata.org/uploads/160524_PP5_REACH_FINAL_WEB.pdf
2. **Expert Patient Programme: Improving antiretroviral treatment access and quality of care for infants, children and adolescents**
http://www.teampata.org/uploads/160428_PP4_ExpertPatient_v3_WEB.pdf
3. **GOKidz: A play-informed, caregiver focused approach supporting children living with HIV**
http://www.teampata.org/uploads/Go%20Kidz_WEB.pdf
4. **Grab the Gap: Creating opportunities for HIV-positive school leavers**
http://www.teampata.org/uploads/Grab%20the%20Gap_WEB.pdf
5. **One-stop adolescent shop: Delivering adolescent-friendly sexual and reproductive health, HIV and TB services**
http://www.teampata.org/uploads/Grab%20the%20Gap_WEB.pdf

Resources & links

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