

SOUTH AFRICA:  
COMMUNITY ACCESS AND ADHERENCE PROGRAMME AND THE ARV ROLLOUT

The Cinderella of Care

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**ABSOLUTE RETURN FOR KIDS** aims to ensure that fewer children are orphaned by HIV/AIDS by providing increased access to antiretroviral treatment for children, their carers and spouses. A British-based, private donor NPO children's charity aims at contributing to the rapid government scale-up of ARV rollout throughout South Africa.



Patients with poor adherence are at risk of treatment failure and are being targeted urgently for adherence improvement.

Patient Advocate (PA) – developed by ARK(SA)

- PAs play a significant role in achieving treatment success through adherence support
- ARK trains local community people and existing community health care workers and home based carers to become community adherence supporters.

To ensure the best outcomes for adherence it is critical to engage an informed patient in their plan of care.

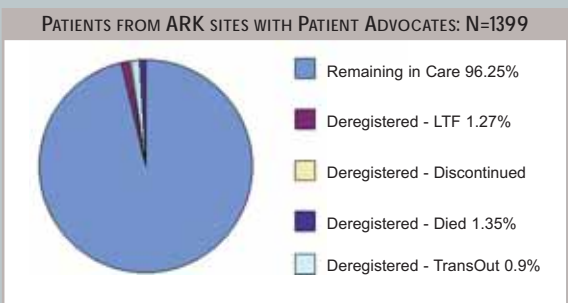
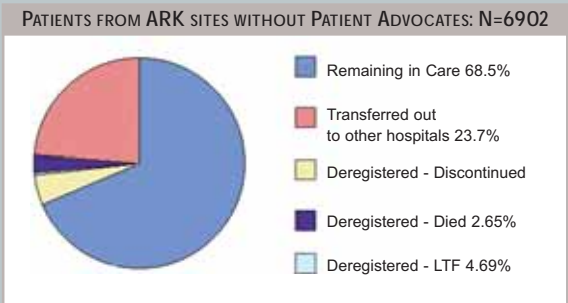
Why Community Workers?

- They are part of the community and know the culture and norms of the specific area.
- They are able to enter households, engage with community members.
- Are better able to determine the psycho-social service needs and able to coordinate that these needs are met.
- They are able to form a special bond between the client, health facility and their family.
- They are an important source of patient and family information.
- They are the link with health facilities/social resources
- **Community Health Workers** have competencies in health promotion, primary health care and health-resource networking and coordination.
- **Home Based Carers** are trained in community adherence.

Community workers must be absorbed into a long-term comprehensive community care program.

The development of the Patient Advocate in the Western Cape & KwaZulu-Natal:

Community participation was crucial in the identification of this specific worker. With the input of community and NGO leaders, criteria were developed to identify suitable community workers able to provide adherence support. The number of community workers needed in the area covered by the clinic is based on the estimated number of patients requiring ARVs now and in the near future.



Personal Challenges for the community workers:

- **Working independently, responsibly** within a community and with health personnel.
- **Personal conduct:** Building and developing professionalism within their code of conduct, respecting clients’ human rights and confidentiality.
- **Patients trust:** Building and developing.
- **HIV and ART knowledge:** Must recognise potentially serious problems and side effects and refer appropriately.

Training:

ARK has developed, assisted by ASRU (UCT), a training programme on ART adherence.

Impact of the community worker in the adherence program:

1) Clinical:

- They are a **dynamic link** between the health facility, their community and the patient.
- They complete the **circle of care**.
- They **interpret and translate** patient’s fears and help overcome language difficulties.
- They give regular **health talks** to waiting patients at the clinic.
- Active in **support groups**, ensure they occur and provide ongoing support for them.
- Assist in **referral** to appropriate services for nutrition support, welfare grants etc.
- **Escorts** patient to various points in the clinic to facilitate flow between services.

2) In the community:

The community adherence care workers help in the following ways:

- **Education** – informing communities on HIV etc.
- **Disclosure and stigma:** Help families and communities understand and accept the disease process through education and support of the PLHA.
- Facilitate understanding of **Traditional healers** and their traditional herb and their impact on ARVs and the client.
- **Children**, help in removing barriers to children accessing treatment, care and support etc.
- Assist patients accessing social services, social grants and poverty alleviation programs.

3) On the individual patient:

A small qualitative review revealed that:

1. The PAs/HBCs/CHCWS helped in alleviating depressive affect and restored self-esteem, by being role-models who demonstrated that one “can live positively with HIV” by staying in care.
2. Patients tend rather to ask the PAs and HBCs about their concerns and problems with medication rather than the doctor or nurse. Only when they have discussed the problem with the PA or HBC would they mention it to the doctor or nurse.
3. Patients had no preferences in terms of gender, age or HIV status of the PAs and HBCs.

Challenges:

- **Contribution of Community adherence support workers remains unrecognised.** There is inadequate research able to quantify the true added value to the ART treatment programmes to date. How does one support clinic based health care workers unable to support patients in their homes and communities?
  - This is an opportune moment to undertake quantitative analysis to show the true value of these interventions on treatment outcomes. There are clear trends as shown above but are they accurate and durable?
  - As there is little hard evidence to support community adherence support there are several challenges that need to be overcome.
- **Sustainability:** There is a need for community support in the form of community adherence workers able to support clinic based ART rollout. This ‘new cadre’ of worker could be part of the answer to the problem facing South Africa. The poor TB cure rates in SA has

spurned on the Government to providing for community interventions they hope ensures improved adherence to TB treatment linked to ART adherence support.

- Financial support appears to be possible through the integration and support by the Expanded Public Works programme; a partnership with the Dept. of Health, Education and Social Services.
- **On going training and support** for these lay workers is crucial as more information about improved care comes to light.
- **Ensuring the same degree of adherence support from all types of community workers** through training.
- **Appropriate financial recompense** for the work undertaken.
- **14000-20000 community adherence workers are needed** (1:70/100pts) to support the patients targeted by the SA ARV rollout programme by 2008/2009, indicating that urgent wide-scale training is required to meet this need. This is possible in the public sector, but is potentially problematic in the private health/insured sectors, the mining industry and the military where the community workers play less of a role.