

# A qualitative study of community home-based care and ART adherence in Swaziland



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## Introduction

The expansion of antiretroviral therapy treatment (ART) has transformed HIV / AIDS into a chronic disease in many parts of the world. However, successful adherence is essential to reaping the benefits of disease chronicity. **This study explored the perceived impact of community care supporters on ART adherence in rural Swaziland** to better understand potentially **innovative mechanisms of treatment support** in high vulnerability settings.

## HIV epidemiology and ART coverage

Adult HIV prevalence: 26%  
Peak prevalence women age 25-29: 49%  
Peak prevalence men age 35-39: 45%

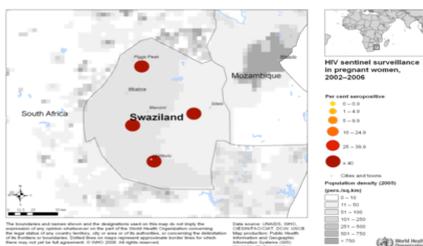


Figure 1. Geographic Distribution of HIV Prevalence in Swaziland (Shiselweni district is in the south)

Swaziland's **59% ART coverage** (2009) is much higher than the average sub-Saharan coverage of 28% (2008). This higher rate both compels and creates opportunities for innovative adherence support.



Figure 2. Shiselweni district. Purple line marks Swaziland's southern border with South Africa. Red ribbons denote SHBC served communities

## Methods

The Shiselweni Reformed Church Home-based Care Organization (SHBC) has 750 care supporters and 2,500 clients across 27 communities (Jan 2011).

Face-to-face semi-structured questionnaires were conducted with **79 HIV positive clients** (purposively sampled) to explore experiences of SHBC care supporters. An aim of the study was **to determine whether and how PLWH felt community caregivers facilitated ART adherence** in a high stigma and economically impoverished setting.

## Results

Participants felt care supporters were instrumental in facilitating ART adherence and to improving overall wellbeing. Since a care supporter began visiting, approximately:

**53% indicated they would have died, some from suicide**

*"If the caregiver didn't come to my house [that first time], I was ready to commit suicide because I know the disease that I have is incurable."*

*"The caregivers teach me how to care for myself with this condition [HIV] and to live my life."*

**27.9% sought HIV testing after a care supporter**

*"Maybe my husband would never have gone and tested or gotten on treatment. My mother-in-law didn't want us to test, and she doesn't want me to talk to other young wives about HIV or to encourage them to test. Even my father-in-law is HIV positive, but still my mother-in-law wants to hear nothing about HIV."*

**31% initiated ARVs**

*"I could have died because the care supporter is the one who came and told me all about the ARVs and TB tablets."*

**92% felt that their health had improved**

*"Sometimes there are side effects. The care supporter is always there for me, telling me, 'go straight to the doctor and tell him.'"*

## Discussion

*"I don't understand things about the sickness... At times, I may think I'm not HIV positive and may want to stop the ARVs, but [the care supporters] answer my questions."*

Medication regimens explicated to patients at the clinic must be 'translated' into individuals' daily practices. Care supporters are integral to this translation in order that adherence become a habit. Constant comparative analysis of reports suggested the indispensability of:

1) **real-time interactions** between clients and caregivers as problems arise

2) the **'care relationship'** is the **'intervention'**, providing lay counsel and material assistance when clients suffered side effects, stigma, and other obstacles to adherence

3) **cultivating client-caregiver 'talk'** to:

- enhance treatment literacy
- reduce felt stigma
- challenge social pressures to desist from ART

Success based on:

**Organizational intervention → Social transformation**

**in subjective meanings** of being HIV positive

**in caring for PLWH – new forms of social relations**

**Key social processes that affect adherence practices.**

## Conclusions

Findings strongly suggest that **CHBC may positively impact ART (and TB) treatment adherence**, which would strengthen national and donor plans to decentralize and integrate health and social welfare services.

The study concluded that **PLWH experiences of CHBC are critical variables** in successfully implementing the **UNAIDS Treatment 2.0 agenda**, notably Pillar 4, increasing HIV testing uptake and care linkages, and Pillar 5, strengthening community mobilization.

## Recommendations

- 1) Comparative evaluations of settings where CHBC operates vs. where none is extant to assess the impact on PLWH health and care practices;
- 2) Comparative studies to determine the significance of stipends on caregiver impact, wellbeing, and retention.
- 3) To determine the total impact of CHBC on individual and collective wellbeing, evaluation studies are needed determine whether there are ripple effects from CHBC clients to household members with respect to HIV-healthy practices, e.g., HIV and TB testing, and treatment uptake/adherence.
- 4) Identify productive linkages with the formal and informal health sectors to help to dispel the confusion and misinformation that appears to fuel HIV denialism and discourage ARV adherence.

## Literature cited

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