

## With a little help from my friends: demand for membership of HIV/AIDS support groups among public sector ART clients in Free State province, South Africa

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## Background (1)

- An integrated, multi-faceted response is required for an effective, sustainable ARV treatment programme
- Sustained, long-term adherence crucial
- HIV/AIDS support groups a potentially important source of adherence and psychosocial support to ART clients
- Yet, little is known regarding the demand, access and willingness-to-pay for belonging to an HIV and AIDS support group

## Background (2)

- Rhine (2009: 369) points out that support groups in the context of the African HIV epidemic are more than "spaces for discussion of social and health well-being" or "institutions functioning solely to cultivate self-responsible and economically empowered patients" and fulfill other functions in communities
  - Simoni et al (2007) conducted a RCT to evaluate the use of peer support groups as a tool for enhancing adherence to ART, but found no significant treatment effects... yet, the authors attribute their null finding to the short duration and low intensity of the intervention as well as the heterogenous nature of their study population
- ... a preliminary search of the literature failed to reveal any other evaluations of group-based adherence support interventions for antiretroviral treatment

## Objectives

- What is the current level of access to HIV and AIDS support groups among public sector ART clients?
- What do we know in regards to the organisation and activities of these HIV and AIDS support groups?
- What is the unmet need and/or demand for membership of an HIV and AIDS support group among public sector ART clients?
- How much are public sector ART clients willing to pay to belong to an HIV and AIDS support group?
- What are the correlates of demand, access and willingness-to-pay for membership of an HIV and AIDS support group?
- What are the implications of the above findings for the potential implementation of groups-based adherence and psycho-social support groups for public sector ART clients in resource poor settings?

## FEATS study design (1)

- Effective Aids Treatment and Support in the Free State (FEATS) study
- Prospective cohort study
- Experimental design, combining:
  - Group time-series, quasi- or field experiment to evaluate impacts of 'ARV treatment'
  - Zelen-type double randomised consent design to evaluate 'peer adherence and nutritional support' interventions

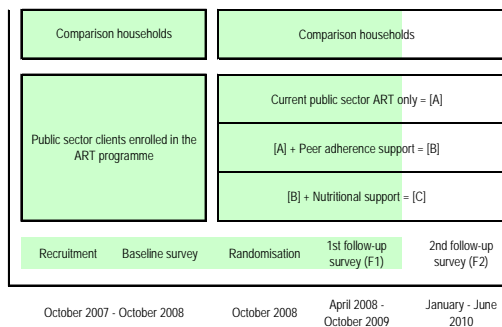
## FEATS: study design (2)

- ART nurses working at 12 phase-I ART clinics across five Free State districts recruited public sector ART patients into the study during a 12-month period [Oct '07 to Oct '08]
- Inclusion criteria:
  - Adult (18+ years)
  - Initiated ART in past 4 weeks
  - Resides in community where clinic based
- Comparison households: randomly sampled from communities where 12 clinics are located

**Figure 1: Study design (FEATS)**

<p><b>Group A:</b></p> <p>216 ART households receiving treatment and support provided in the existing programme</p>	<p><b>Group B:</b></p> <p>216 ART households: A + bi-weekly visits by trained ARV peer adherence supporter (PAS)</p>
<p><b>Group C:</b></p> <p>216 ART households: A + B + nutritional supplement (canned food) delivered by PAS</p>	<p><b>Group D:</b></p> <p>208 comparison households randomly sampled from the relevant communities</p>

**Figure 2: Study design (FEATS)**



## Study design (3)

- Ethical clearance:
  - Faculty of Health Sciences, UFS [ETOVS 145/07]
  - National trial register [DOH-27-0907-2025]
  - NIH trial register [NCT00821366]
- Data collection (baseline/follow-up):
  - Patient survey
  - Clinical records in patient files
  - Household survey
    - Household: socio-demographics, education, morbidity, mortality
    - Household respondent: income, expenditure, debt, savings
    - Individual interviews (10-14; 15; 16+ years): various data
  - Facility survey
    - ARV coordinators/managers at clinics/hospitals
    - Provider questionnaire: ART staff at clinics/hospitals, lay workers

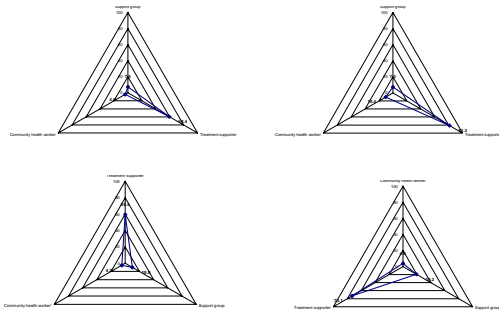
## Data and Method

- Individual and household-level data for **655** ART patients enrolled in the Free State province's public sector ART programme in 2007/08
- Descriptive analysis:
  - Access
  - Need/Demand
  - Cost
  - Willingness-to-pay
  - Organisation
  - Activities
- Regression analysis:
  - Correlates of demand, access, and willingness-to-pay

**Figure 3a: Access to support groups, treatment supporters and community health workers**

	Support group	Treatment supporter	Community health worker
Previously only	2.0	2.3	2.0
Currently	7.3	59.4	4.0
Never	90.7	38.3	94.0
<i>Total</i>	<i>100.0</i>	<i>100.0</i>	<i>100.0</i>

**Figure 3b: Access to support groups, treatment supporters and community health workers**

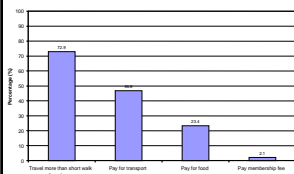


**Figure 4: Access, need, cost and willingness-to-pay to belong to an HIV/AIDS support group**

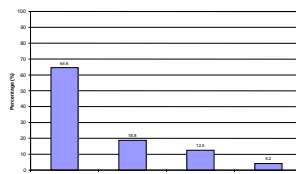
Access (yes/no)	Need (yes/no)	Pay (yes/no)	Cost (ZAR)	Willing to pay (yes/no)	Willingness-to-pay (ZAR)
Previously [13/655 = 2.0%]	84.6% [11/13]			54.5% [6/11]	Mean: R30.00 Median: R15.00 IQR: R10.00 - R30.00
Currently [48/655 = 7.3%]		58.3% [28/48]	Mean: R18.90 Median: R9.00 IQR: R8.00 - R20.00	10.4% [5/48]	Mean: R50.00 Median: R30.00 IQR: R20.00 - R40.00
Never [594/655 = 90.7%]	68.0% [404/594]			61.4% [248/404]	Mean: R24.78 Median: R20.00 IQR: R10.00 - R28.00
<b>Total</b>	<b>68.4%</b> <b>[415/607]</b>			<b>55.9%<sup>***</sup></b> <b>[259/463]</b>	Mean: R25.39 Median: R20.00 IQR: R10.00 - R30.00

Notes: \* Proportion of current support group members reporting either actual costs for last visit or normally incurring cost for transport, food or membership to participate in meetings; \*\* Reflects proportion of current support group members who are willing to pay an additional amount to belong to a support group; \*\*\* Reflects proportion willing to pay among (a) current support groups members and (b) non-members expressing a demand for membership.

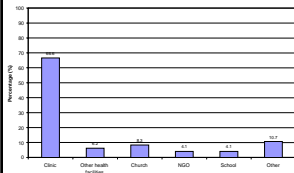
**Figure 5: Accessibility of support groups**



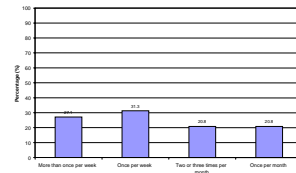
**Figure 6: Organisation of support groups**



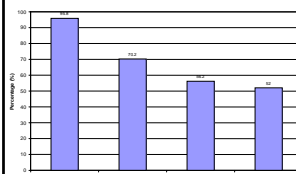
**Figure 7: Meeting place of support groups**



**Figure 8: Frequency of support group meetings**



**Figure 9: Composition of support groups**



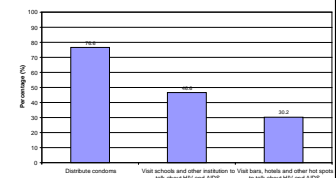
**Composition:**

Comprise persons on ART, HIV-positive persons not yet on ART, HIV-negative persons, and ones whose status is unknown to the member who responded to the survey... this has NB implications?

**Activities:**

Relatively high participation in range of prevention activities... this has NB implications?

**Figure 10: Participation of support groups in prevention activities**



**Table 1: Correlates of need, access, payment and WTP**

	NEED	ACCESS	PAY	WTP
Age	0.001	0.032	-0.004	-0.008
Age <sup>2</sup>	-0.001 *	0.000	0.001	0.001
Education (comparison = none)				
Some primary	-0.135	-0.701	0.463	0.397
Some secondary	-0.172	-0.584	0.650	0.553 **
Grade 12 or higher	0.341	-0.953 **	0.707	0.615 **
Household size	-0.012	0.040	0.123	-0.020
Dependency ratio	0.346	-0.146	-0.546	0.614 *
Marital status (comparison = single)				
Married and cohabiting	0.447 ***	0.435 *	-0.002	-0.044
Married but not cohabiting	-0.573 ***	0.760 **	0.117	0.073
Divorced, separated or widowed	0.031	0.139	0.074	0.085
Single	0.062	0.033	-0.119	-0.196 ***
Disclosure (comparison = disclosed to none)				
Disclosed to some only	0.256		-0.255	0.209
Disclosed to all	0.623 ***		-0.174	-0.198
Avoidant coping	0.027	-0.143 ***	0.070	0.030
Supportive coping	0.335 ***	-0.038	0.112	-0.029
Positive coping	-0.470 **	0.135	0.303	0.208
Acceptance coping	0.953 *		-0.365	0.614 *
Health-related quality of life (EQ-VAS)	-0.008 **	-0.003	0.002	0.004
Reported symptoms of depression (yes/no)	0.347	0.154	0.615 **	0.592 **
Reported symptoms of anxiety (yes/no)	0.127	-0.627	0.297	-0.083
Access to treatment buddy (yes/no)	-0.012	0.576 **	0.016	0.116
Visited by community health worker (yes/no)	0.270	0.455	-0.767 **	0.204
Previously belonged to a support group (yes/no)	1.024 **		-0.473	0.308
Treatment duration (months)	0.041	0.002	-0.142 **	0.145 **
Previously on ART (yes/no)	0.021	0.486	1.015 **	0.172
Sample (n)	510	394	372	240
Wald chi2 or F statistic (p-value)	75.71 (<0.001)	50.04 (0.003)	45.15 (0.028)	2.13 (0.001)
Pseudo R <sup>2</sup> or R <sup>2</sup>	0.166	0.230	0.092	0.174
Successful prediction (%)	70.6	89.3	63.7	

Note: Results are for probit (NEED, ACCESS, PAY) and linear (WTP) regression models respectively. WTP model includes non-zero WTP values only. Models were also adjusted for gender, self-reported adherence, income, employment status, and time known HIV+ status.

**Summary: regression results**

**DEMAND** greater among:

- ART clients with partners, both cohabiting or not
- ART clients who have disclosed to all significant others
- ART clients exhibiting supportive coping strategies
- More unhealthy ART clients
- ART clients who have previously belonged to a support group

**PAYING** more likely among:

- ART clients belonging to larger households
- ART clients exhibiting symptoms of depression
- ART clients who had been on treatment for a shorter period of time
- ART clients who used ART prior to joining the public sector ART programme

**ACCESS** higher among:

- ART clients who are married but are not living with their partners
- ART clients not exhibiting avoidant coping
- ART clients with access to a treatment supporter

**WILLINGNESS-TO-PAY** higher among:

- ART clients with higher levels of education
- ART clients perceiving less HIV/AIDS-related stigma
- ART clients exhibiting symptoms of depression
- ART clients who had been on treatment for a longer period of time

## Limitations

- *Generalisation*: data does not allow generalisation beyond the South African and even perhaps beyond the Free State setting
- *Selection processes*: choices of demand → access and of pay → WTP may be characterised by selection, thus requiring estimation of Heckman selection models
- *Network-like nature of support*: use of SEM may be feasible given multiplicity of (other) support types, which may be substitutes or complements for support groups
- *Simultaneity and/or endogeneity*: cross-sectional data cannot reveal dynamics of demand for and participation in HIV and AIDS support groups among public sector ART clients
- *Study dynamics*: introduction during experimental phase of the study of individual peer adherence support are likely to crowd out demand and WTP for support groups

## Conclusion (1)

- Large, unmet demand for HIV and AIDS support groups among public sector ART clients
- ART clients attribute relatively large, non-zero benefits to membership of a support group
- Nature of membership and activities of existing support groups suggest that such groups may play an important role, not only in treatment support, but also in HIV prevention activities
- Importance of coping, disclosure, stigma and depression as correlates of demand, access and WTP hint at the important role of support groups as means of psycho-social support to ART clients
- Importance of past support group membership and access to treatment supporter implies that complementarity and substitutability of different means of (adherence) support should be investigated

## Conclusion (2)

- Further research is required to determine the cost of effective, scalable models for providing HIV/AIDS support groups to ART clients in resource-poor settings
- These cost estimates are required to conduct a cost-benefit analysis (CBA) of such intervention, which would aid in determining the feasibility of investing in the scale-up of HIV/AIDS support group interventions as part of effective, sustainable ARV treatment programmes
- FEATS: we are looking at conducting an evaluation of group-based adherence support to patients between the second and third follow-up surveys of study participants

**Figure 11: Alternative study design (FEATS+)**

